S. HRG. 98-383

COMMUNITY ALTERNATIVES TO INSTITUTIONAL CARE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

FIRST SESSION

HARRISBURG, PA.

JULY 6, 1983

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE

25-697 O WASHINGTON : 1983

S141-16

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COMMUNITY ALTERNATIVES TO INSTITUTIONAL CARE

WEDNESDAY, JULY 6, 1983

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Harrisburg, Pa.

The committee met, pursuant to notice, at 9:42 a.m., in the William Penn Museum Auditorium, Harrisburg, Pa., Hon. John Heinz, chairman, presiding.

Present: Senator Heinz.

Also present: Nancy Kingman, professional staff member; and Angela Thimis, hearing clerk.

OPENING STATEMENT BY SENATOR JOHN HEINZ, CHAIRMAN

Chairman HEINZ. The Special Committee on Aging will come to order.

Ladies and gentlemen, good morning. This is a hearing of the U.S. Senate Special Committee on Aging. I am the chairman of that committee.

Today, what we want to do, is to look at what is being done in Pennsylvania to place the elderly and the developmentally disabled in the community.

After we have heard the testimony of our witnesses this morning, I intend to take what I have learned back to Washington, D.C., so that my colleagues, both on the Aging Committee and the Senate Finance Committee, which is a committee of legislative jurisdiction, will learn more about what types of alternatives to institutional care can be implemented on a broader scale.

It is my judgment that we do need a more coherent national policy that stresses a continuum of service choices. Today's policies, at best, although many efforts are being made to improve them, are nonetheless fragmented, and emphasize institutional care, and erect roadblocks to further community placement of our elderly and developmentally disabled citizens.

Local communities have the pieces necessary, in many cases, to forge a total delivery system to better treat the needs of the elderly and developmentally disabled.

What is missing, however, is one very critical ingredient; namely, the resources and the unifying structure to manage individual cases properly.

Today's standard delivery system of care is not even a system. Despite the availability of new, alternative delivery systems which often can better meet the needs of a client, most of the treatment

is still provided in an institutional setting. The mere diagnosis of old age or severe disability has become itself a diagnostic dead end.

We more or less doom certain individuals to what is tantamount to human warehousing. Yet, in recent years, we have made great strides in the field of medicine, and there is a wealth of information available on the medical and therapeutic techniques necessary to help the elderly and the severely disabled care for themselves.

Given this medical progress, we should be striving to maximize self-care and allow all citizens to lead normal lives in the least restrictive setting.

Our goal should be to support the family and community structures, not to supplant them.

In the past decade, this Nation has made great strides in the deinstitutionalization efforts. A series of court decisions prompted States to empty their institutions and move thousands of mentally ill, disabled, aged, and handicapped persons into community-based settings.

By the mid-1970's, most patients who were discharged from State institutions were placed in boarding homes where Federal SSI funds paid for most of the cost.

The Nation's boarding home industry, once a cottage industry, grew quickly into a highly profitable business. During these early years of the deinstitutionalization movement, however, there were some serious problems. As recently as between 1977 and 1981, over 143 persons lost their lives in boarding home fires.

There were tragedies other than fires in boarding homes, which were documented by the General Accounting Office and committees of Congress. Problems included forging patients' checks, leaving patients' gangrene untreated, and documented cases of dehydration and malnutrition among patients.

In response to these problems, Congress enacted the Keyes amendment to the Social Security Act. This amendment simply required States to license and regulate boarding homes.

Today, if boarding homes are found to be unsafe, the U.S. Department of Health and Human Services can withhold the SSI checks going to residents in those homes. There are also minimum standard requirements and onsite inspections of boarding homes.

Congress, as well as the courts in the States, have learned that many residents of institutions may be candidates for placement in the community, but only if such placements are carefully assessed and monitored.

Today, Federal and State statutes governing community-based living arrangements, such as boarding homes, now seem to be keeping pace with a continuing trend of deinstitutionalization.

Meanwhile, because of the types of patient abuses which can take place in large, isolated public institutions, we need to continue to improve upon the placement criteria which are used in determining the medical and therapeutic needs of the elderly and developmentally disabled prior to their placement in community-based settings.

To date, here in Pennsylvania, we have depopulated a number of State institutions, but many institutional inmates still are on waiting lists for community placement.

I don't happen to believe that all State institutions should be closed. But for those residents confined to institutions with a documented history of patient abuse, I think we must move quickly to find more suitable living arrangements.

Just this year, the latest sorry chapters in the continuing tale of patient abuse were unfortunately written here in Pennsylvania. Female residents were raped at Ebensburg Center. Interestingly enough, this is one of the State's more expensive centers.

Also, on January 24 of this year, a 26-year-old male resident of Woodhaven, another State center for the mentally retarded, died from collapse associated with forcible restraint.

Clearly, we have some alarming problems. Equally clear, we need a coherent Federal policy on the future direction of deinstitutionalization. Community placement should be handled on a case-by-case basis, and a placement determination should be made by qualified professional people.

We have a very distinguished group of witnesses here today to help us sort out the issues, problems, and challenges before us as we develop a national policy. And so, in that spirit, I want to welcome our witnesses here today. I think they will shed a good deal of light on the problems before us.

We are honored and pleased to have Hon. Walter Cohen, secretary, Pennsylvania's Department of Welfare.

Secretary Cohen, would you please join us. I see you are accompanied by members of your staff, so please bring them with you, if you so desire.

May I say for those in the audience who may not be so aware, although I suspect most are, Secretary Cohen is somewhat newly appointed in his job, about 3 or 4 months. Previously, he was a consumer advocate of Pennsylvania, and a prison master for the court of common pleas in Philadelphia in 1973 and 1974.

He was on the staff of the Philadelphia district attorney's office in 1967 through 1973, which, for those of you who are not students of history, was when my colleague, Senator Specter, was the district attorney of Philadelphia. And, in spite of the fact that I went to Yale, I am not at all adverse to the fact that Secretary Cohen holds degrees from Harvard University as well as the University of Pennsylvania Law School.

Secretary Cohen, we welcome you. We thank you. Please proceed with any opening remarks and comments you want to share.

STATEMENT OF WALTER W. COHEN, HARRISBURG, PA., SECRETARY, DEPARTMENT OF PUBLIC WELFARE, STATE OF PENNSYLVANIA; ACCOMPANIED BY JENNIFER HOWSE, DEPUTY SECRETARY FOR MENTAL RETARDATION; AND GERALD RADKE, DEPUTY SECRETARY FOR MEDICAL ASSISTANCE

Secretary COHEN. Thank you, Senator Heinz. I am now completing my first 4 months on this new job and aging fast.

I'd like to introduce first, on my right, deputy secretary for mental retardation, Jennifer Howse; and on my left, deputy secretary for medical assistance, Gerald Radke.

I'd like to start, if I may, Senator, with a footnote, and that is to express, from the standpoint of the Pennsylvania Department of

Public Welfare, and the many problems that we encounter dealing with our general assistance welfare population, our appreciation and commendation to you for the legislation that you have introduced to deal with the social security supplementary disability income problem.

In Pennsylvania, as I am sure you know, we last year enacted a new general assistance law, which deals with the question of capability to work on the part of general assistance recipients without dependents between the ages of 18 and 45, a matter which is currently now before the third circuit.

We, in that assessment process of the determination of capability to work, use the opinions, need the opinions of physicians, including psychiatrists and psychologists, in order to allow us to reach what we would be comfortable with, to be an adequate determination of ability to work. And I think that the Federal system, which you are addressing and which you are seeking to change, by way of change in the Federal regulations, has not kept pace with the trend toward deinstitutionalization, and a movement of citizens, both from the mental health hospitals and the mental retardation centers here in Pennsylvania, into the community.

So that the determinations that are made on that issue of disability are not in pace with the best medical diagnoses that are possible, and the end result is that too many people, I think, have been harmed by decisions that, I should also add, are not made by the Pennsylvania Department of Public Welfare, but are made by the Department of Labor and Industry following the regulations set forth by the Federal Government.

So, addressing that very important problem, as you have done, takes us, I think, a step closer to solving some of our more serious problems in this State. And I would expect also that was a part of the response Secretary Margaret Heckler showed, as a result of the fact that she knew that there was such important interest in the Halls of the Senate on that issue.

Chairman HEINZ. If I might interrupt, Mr. Secretary, first, I thank you for your kind words. It necessitated, however, finding a Congressional Medal of Honor winner that the President himself had previously decorated, who had been declared not disabled, even though he had two pieces of shrapnel in his heart.

And it is my hope that the progress that Secretary Heckler has made will not be the end of the progress made by the administration, because I believe that failure to recognize that the continuing disability review system is causing very unfair and needless hardships to many people, is political dynamite, and I do not want to see it blow up in the face of the Reagan administration.

I thank you very much for your kind words.

Secretary COHEN. That is, of course, part of the overall issue that we are addressing today, the subject of deinstitutionalization. What I would like to do, and I have submitted several pages of prepared testimony,[1] is to attempt to summarize that testimony by setting forth some of the more salient facts on where we are in Pennsylvania, by mentioning some of the new initiatives that we are undertaking this year, and in the years ahead, on the movement toward

[1] See page 7.

deinstitutionalization and community care and treatment, and then to suggest some of the Federal remedies, some of the Federal approaches, that would be helpful in this effort.

Currently, in the Commonwealth, we provide $1.2 billion in Federal and State money for long-term care services and medicaid covers about 75 percent of those costs.

More importantly, the amount of these funds necessary to meet the needs of Pennsylvanians requiring long-term institutional services has grown ninefold over the past 10 years.

If we look at our mental retardation services, we would see a reflection of this movement and these ever-growing expenditures. Over the past 4 years, in State funds alone, our budget for community-based services has grown from slightly over $100 million a year to $157 million a year, or an increase of about 50 percent in 4 years for community care for the mentally retarded.

For community intermediate care services for the mentally retarded, that budget has gone up threefold, from $8 to $24 million, again over a period of the past 4 years.

In terms of our current budget, our community service dollars account for 57 percent of the total State budget for mental retardation. A look at the population in the mental retardation centers around the State, those from 1970 until today, the population has gone down from 12,500 to 6,800 clients currently residing in our centers.

In fact, three of these centers have been phased out over the past 4 years, a reflection of that movement away from the centers and into a variety of community services.

The community living arrangements have provided 1,600 facilities around the State serving some 4,500 clients, many of whom have been residents of these centers. And I think just that 4,500 added to the 6,800 shows the difference from the population in 1970 of 12,500 to the population today.

These numbers are a mirror of the direction of this Commonwealth toward the important need for developing community-based services and care for not only our mentally retarded citizens, but also the elderly in Pennsylvania. I think that we have shown, and have to continue to show, a very real concern that these citizens are provided with an opportunity to receive care in the community wherever possible.

Our goal is, I think, to move as organized and as swiftly as we can toward community services with a number of demonstration projects and a number of initiatives securing waivers of Federal requirements, for us to be able to maximize the Federal dollars we receive, minimize the amount of State money that we would have to pay out where Federal money could be available, and move toward a comprehensive long-term care system.

You will hear, as I see from the list of witnesses, in detail, about the channeling project in Philadelphia, and I will leave that for the people who are from the Philadelphia Corporation of the Aging who are more directly involved in that effort, which is funded through the department of public welfare.

An interdepartmental long-term care planning committee that Governor Thornburgh established a couple of years ago has developed a first draft of a long-term care State plan. Pennsylvania now

provides a State supplement of $115 monthly to SSI recipients living in domiciliary care facilities and licensed personal care boarding homes.

The amount of the assistance has enabled thousands of Pennsylvanians to remain in the community and avoid being placed in institutions.

The medical assistance program, through increased fees, has made community medical services more widely available.

We have used the assistance which we have received under the Federal emergency jobs legislation to aid our efforts. Right now, we are preparing to put about $9 million of the $14 million in social services money into a new program to provide in-home services, and to use some of our general assistance recipients as the people who will work on the provision of those services.

I think that if we can administratively develop that program, we would be both helping increase the number of people in our community who are trained for health care, and at the same time, providing necessary services to people who might otherwise be institutionalized.

The preadmission assessment program will begin as pilot projects in Luzerne, Wyoming, Philadelphia, Allegheny, and York Counties. That effort is to assess what the necessary and most desirable level of care would be on an individual basis.

It will be reviewed upon the completion of the pilot project. And I would hope it would be expanded on a statewide basis over the next couple of years.

One of the most important efforts—to return again to our focus on the mentally retarded—one of our most important efforts is, and must be, the development of waivers for placement in community facilities. We have developed, thus far, six waivers.

We have received Federal approval for one of them for Philadelphia. We are hoping to develop a couple more waivers for the physically disabled and mentally alert, and one for the elderly long-term care population.

But that waiver process, I think, is what would merit some very close attention from your committee because of what has happened, as I see it; and perhaps from my perspective, relatively new to the system, I can comment on the broad overview. It appears to me that the impact of title XIX, and of the necessity to apply on a case-by-case, or county-by-county basis, for waivers of the institutional requirements, is really to put the incentive first on large institutional settings for the mentally retarded, and to force the States to present their case for what we would see as the more desirable method of care for the mentally retarded.

These applications require voluminous documentation. And we now understand that the Health Care Financing Administration would perhaps be operating under new regulations, if Secretary Heckler approves what we understand is before her at this time, to limit the amount of reimbursement to what is set forth in the waiver package and provide a further disincentive, not only to Pennsylvania, but to any State that is trying to develop a broad-based community care program.

I think that the Federal legislation could address this issue and could more directly address the need for incentives toward commu-

nity care. That is not to say that we are planning to, or should be planning to, as you mentioned in your opening remarks. We are in agreement with you, and we are not moving toward the elimination of all large facilities. But we are moving toward a mix of care, a choice of types of facilities, size of facilities, and location of facilities, in order to maximize the availability of the appropriate resources for a wide variety of clients who are entitled to these resources, and a Federal legislative package that I think could address the incentive toward community care, while preserving, as we would see it, the State's prerogative of what we would determine to be the best possible system.

I think that Federal legislative effort would be a very important one in terms of moving Pennsylvania and the other States toward the 1980's, a better arrangement for a mix of both institutional and community-based facilities. And when I mention community-based and institutional facilities, I am referring, again, to a variety of types in terms of size and service provided.

It is obvious that we in Pennsylvania have been moving to develop a long-term care system which will be responsive to the needs over the next several years, for both our elderly and our mentally retarded populations.

We are looking to the Federal Government to assist us in accomplishing the goal that I think we all share—providing flexibility to design programs to fit the needs of all of our residents.

As we move in this direction, we face the major problems of overall programs' costs, control over the use of the programs, the continued demand for institutional beds, and the replacement of informal care by publicly financed health services.

For all of us who are here—and I would assume most of us who are here are involved in the social service system, the provision of care to the elderly, or the mentally retarded—we are looking to have assurances that we can rely on Federal financial assistance, and that we will work together to find acceptable limits on the use of our resources, so that we can provide the best possible level of care. And that is the goal of the Department of Public Welfare in Pennsylvania. It is a look to the service to the clients of the department, to maximize the Federal dollars for that service, and to provide the proper level and type of service on an individual basis for each person in the Commonwealth.

Chairman HEINZ. Mr. Secretary, I want to thank you for your excellent testimony. I want to commend you on your goal, one that we share, which is to develop choices. Choices that are appropriate to the needs of Pennsylvanians, be they elderly, be they developmentally disabled, be they mentally retarded.

It is by developing those kinds of options that we can allow our citizens to fulfill, to the maximum extent possible, their independence.

And I again salute you on taking to heart that goal.

[The prepared statement of Mr. Cohen follows:]

PREPARED STATEMENT OF WALTER W. COHEN

Before testifying this morning, Senator Heinz, I want to commend you for introducing legislation which would require the Social Security Administration to revise its regulations governing assessment of mental disability for social security disabil-

ity and supplemental security income and assure that psychiatrists or psychologists participate in these assessments. In Pennsylvania, our assistance programs rely on the professional judgment of physicians, psychiatrists, and psychologists when we decide if a disabled person is employable. The criteria used in SSI/SSDI assessments have not kept pace with clinical advancements which now allow treatment for seriously impaired individuals at home and in community settings.

I am pleased to have this opportunity to address a growing concern we all share here today—how do we best provide and pay for long-term care for the elderly and mentally retarded persons as they increasingly return and remain in the community.

Currently, the Commonwealth of Pennsylvania provides more than $1.2 billion annually in Federal and State dollars for long-term care services. Medicaid funds cover nearly 75 percent of these costs. More importantly, the amount of these funds necessary to meet the needs of Pennsylvanians requiring long-term individual services has grown ninefold over the past 10 years.

Specifically, our mental retardation services reflect the direction of these ever-growing expenditures. In State funds alone over the past 4 years, the budget for community-based services has grown from $104.7 to $156.8 million, and the budget for community intermediate care services for mentally retarded persons has grown from $7.9 to $24 million. In terms of the current budget, community service dollars account for 57 percent of the total State budget for mental retardation. In terms of the total population of the mentally retarded persons in State centers, currently, 6,800 reside in the centers today, down from 12,568 residents in 1970. The phaseout of three centers in the past 4 years reflects this steady decline.

These numbers clearly mirror Governor Thornburgh's and the Commonwealth's strong commitment toward the important need for continued financial support and development of community-based services and care for the elderly and mentally retarded citizens in Pennsylvania. This administration's record illustrates an active concern that elderly and mentally retarded Pennsylvanians are provided, when and wherever possible, an opportunity and a choice of receiving care in the community rather than in an institution.

In Pennsylvania, we have spent a great deal of time and energy addressing the issue of long-term care. I believe that it is essential that the Commonwealth view community care as one essential part of a larger continuum of care. The major goal of our long-term care system should be to develop a wide spectrum of services and facilities to provide the specific level of care needed by an individual, and to have other levels of care available as needed. This range of services must include medical, social, and in-home services. Many of these services are found in the community and are appropriate modes of long-term care.

We need to address the initiatives and new approaches which can move us closer to achieving these goals. In Pennsylvania, our efforts to develop a comprehensive long-term care system continue to evolve.

In October 1980, the Department of Public Welfare along with the Departments of Aging, Community Affairs, and Health, began a 4-year long-term care demonstration project. This "channeling" project is exploring the various long-term care system alternatives.

In July 1981, Governor Thornburgh, by executive order, established an interdepartmental long-term care planning committee. The committee has reported back to the Governor, making numerous recommendations, and has proposed a State long-term care plan. Many of those recommendations are under review and several have already been implemented.

Pennsylvania now provides a State supplement of $115 monthly to SSI recipients living in domiciliary care facilities and licensed personal care boarding homes, which will help them pay for their care in the community. This assistance has already enabled thousands of Pennsylvanians to remain in the community and avoid being placed in institutions. The medical assistance program, through increased fees, made community medical services more widely available.

We have used the assistance which we have received under the Federal emergency jobs legislation to aid our efforts. We are preparing to use $9 million of the $14 million provided under the Federal emergency jobs legislation to purchase home care services for Pennsylvanians who have been discharged from hospitals and have left, or otherwise would have entered nursing homes. The home care services will provide jobs for recipients of public assistance, complementing the Commonwealth's efforts to find them meaningful employment, while enabling others to live in the community.

Most recently, another important effort—preadmission assessment—has been undertaken jointly by my department and the Aging Department, addressing an important need of elderly Pennsylvanians.

For some time, it has been clear that we must improve our method of determining if an individual needs nursing home care. This is a planned effort to assess nursing home applicants prior to admission to determine whether nursing home care is, in fact, the best placement.

Preadmission assessment will be initiated as a pilot program in Allegheny, York, Luzerne, Wyoming, and Philadelphia Counties during the coming year with the intent of going statewide after those pilot programs are assessed. I feel strongly that preadmission assessment is critical to insuring appropriate care in the least restrictive setting. In many cases, that will mean community care.

Turning to community care for the mentally retarded, I want to share some thoughts with you on the title XIX home and community-based care waivers, or as they're labeled, the 2176 waivers. The department supports the Federal waivers on the basis of their potential for preventing unnecessary and costly institutionalization by allowing States to use title XIX medicaid funds for community service in a cost-beneficial manner. To date, we have applied for six waivers focused on mentally retarded persons which will use approximately $2.7 million of Federal medicaid funds for community services and will provide community placement to more than 300 people in the Pittsburgh and Philadelphia metropolitan areas. One has been approved, the second is now being reviewed. Four were just submitted last week.

We plan to develop two more waivers, one to serve physically disabled, mentally alert persons, and one to serve an elderly long-term care population. The latter will be coordinated with the development of the preadmission assessment projects.

The waiver approach is not without flaws. While agreeing with the concept of using title XIX dollars for community services, provided that institutional beds are simultaneously closed, I am concerned about the length of time it has taken for a waiver to be approved, and the details that must be provided for in such a waiver. Perhaps Pennsylvania is unique—to satisfy the requirements for merely one waiver application, our appendices were approximately a foot and a half thick and weighed 22 pounds.

I would suggest that, instead of requiring waivers or exceptions to the Federal regulations, the Federal law should be revised to allow a State, through its medical assistance plan, the flexibility to design and implement community services without seeking approval for each individual request.

In addition, we understand that the Health Care Financing Administration and Health and Human Services Department staff are proposing final regulations, now under review by Secretary Heckler, which could pose a threat to this new-found flexibility. These draft regulations would limit the amount of reimbursement made to the States to the established amounts in the waiver applications. Such a restriction, which does not appear to have any foundation in legislation, may well impede States from using the waiver option because of the potential adverse fiscal impact. I am hopeful that this potentially damaging action will be averted.

Taking this concept further, we encourage Federal modifications to alter the emphasis of current medicaid reimbursement policies. The current institutional care incentives should be replaced with similar incentives for community placement of mentally retarded persons. We see a continuing need for institutional placement for some of our population and will rely on vital Federal support in that area. However, we are hopeful that a change in the direction of Federal reimbursement would assist us in placing a larger number of our population in more appropriate smaller community facilities.

The waiver process is only one of several approaches for independent funding sources for community-based long-term care which have been developed within the recent past. However, the flexibility to shift Federal funds to meet the needs of States has been lacking in the present large number of federally funded programs which provide the range of community services. More than a dozen current Federal programs remain inflexible, uncoordinated, and unevenly distributed. These roadblocks make vital linkages at the local level difficult, if not impossible to implement. We must resolve these problems at all levels of government to assure adequate and appropriate community-based and institutional care for our populations in need.

It is obvious, we, in Pennsylvania, have been moving to develop a long-term care system which will be responsive to the future needs of our elderly and mentally retarded population. The Federal Government must assist us in accomplishing what I believe is a goal shared by all of us—providing the flexibility to allow State government in Pennsylvania to design programs to fit the particular needs of Pennsylvania residents.

As we move in this direction, we face the major problems of overall program costs, control over the use of the programs, the continued demand for institutional beds, and the replacement of informal care by publicly financed health services. For all of us here today, we need to have assurances that we can rely on Federal financial assistance, and that we will work together to find acceptable limits on the use of our limited resources, if we are to satisfactorily overcome these problems.

Through all of our efforts to meet the challenge of redirecting our resources to meet the future needs of the long-term care system, we must always clearly understand that the intent of our efforts is to substitute, where appropriate, community care for more expensive institutional care, allowing persons to remain in the community and receive adequate and appropriate care, at a lower cost.

Chairman HEINZ. Mr. Secretary, you have mentioned some of the incentives created by the Federal Government, as you state, that create a bias toward institutional care. In dollars and cents, spell out for us how those incentives operate.

I will assume that the way the Federal reimbursement works under medicaid is that the State puts up less money for institutionalization than it would to provide a community services living arrangement.

But do you have, in effect, a comparison of those reimbursements and costs?

Secretary COHEN. I think that Dr. Howse can probably respond on a dollars and cents basis.

Dr. HOWSE. Senator, the Federal formula that is in place right now for reimbursing services in the publicly operated facilities allows States to earn about 53 cents for every dollar. In other words, roughly half of what we spend is State money and half of what we earn is Federal money for the centers.

Chairman HEINZ. How much is that per person?

Dr. HOWSE. I'll give you a dollar figure, overall, and then a per diem, for this past fiscal year that ended last week. The total funding for the State centers from Federal sources was $160 million, and the total funding for the State centers out of State revenue was $132 million.

And that works out to an overall per diem of something in the area of about $129.

Chairman HEINZ. Per person per day?

Dr. HOWSE. Right.

Chairman HEINZ. Not per bed per day?

Dr. HOWSE. Per person.

You all dropped ratios on us a little bit.

Chairman HEINZ. $70 of that is Federal and $59 of it, more or less, is State.

Dr. HOWSE. That is right.

Chairman HEINZ. Now, community living, what are the State and Federal economics of that?

Dr. HOWSE. From our perspective, it is almost purely a State proposition. Again, to give you 1982–83 dollar figures, the total spent by the State was $131 million for community services. And we also spent about $7.5 million of Federal title XX money that was used to supplement community programs.

There is one area, Senator, that we have worked on, particularly in the last 4 years in the community, which allows us to get the same ratios as we discussed earlier. We have worked to expand the

community ICF/MR program to allow us to earn that Federal reimbursement for privately operated community services.

And again, to give you the numbers, this fiscal year, the total in that program was——

Chairman HEINZ. This is the community ICF?

Dr. HOWSE. That is correct.

Chairman HEINZ. Before you give us those numbers, could you work for the deinstitutionalized people the State costs down to a per diem for me?

Dr. HOWSE. The average for community living arrangements, which is where the majority of the community placements are, Senator, is about $60 a day for the residential service and some support services. And again, that is also all State dollars.

And then you must add to that, to get to a truer cost, about $20 a day for vocational training, or adult day service programs. And then I would estimate that you probably should add maybe another $5 to $10 for other support services, case management, transportation, and so forth.

But the average for residential is $60.

Chairman HEINZ. Exclusive of services?

Dr. HOWSE. Exclusive of day services.

Chairman HEINZ. Which would be provided—the equivalent of those day services that would be provided in an institutional setting?

Dr. HOWSE. That is right.

Chairman HEINZ. So the comparable costs to the State are around $60 for institutionalization, but around $85 or $90 a day for community living?

Dr. HOWSE. That is correct

Chairman HEINZ. Absent some skillful grantsmanship, shall we say, by the State of Pennsylvania.

Dr. HOWSE. That is correct.

Chairman HEINZ. Now, tell us about your skillful grantsmanship. You started to talk about community ICF.

Dr. HOWSE. Community ICF/MR, Senator, has a total budget for the past fiscal year of $56 million. And $24 million of that is State revenue and $32 million of that is Federal revenue.

And we have about 1,800 persons who are recipients of ICF/MR services, private ICF/MR services, in Pennsylvania.

Chairman HEINZ. Let me ask you an obvious question. If it is costing State taxpayers $90 to $95 a day for deinstitutionalized people and only $60 a day for institutionalized people, net to the State, exclusive of Federal money, why is the State deinstitutionalizing people? And does the State claim this saves the State money?

Dr. HOWSE. Well, I think there are a couple of things that need to be looked at. One is that the Federal incentives, as Secretary Cohen's testimony indicated, the Federal incentives have clearly been directed toward institutional care. And I think that it is exemplary in Pennsylvania that the policy has been driven by client need, and has not exclusively been a proposition of where can you chase the Federal dollar the fastest. So I think that is one point that needs to be made.

I think the other point, Senator, is, that there are opportunities now just starting to open up, and again, as Secretary Cohen indi-

cated, we hope that this is an area that you will continue to be interested in.

But there are areas opening up now that would allow us to, in essence, shift dollars that are presently going to finance publicly operated facilities and shift those dollars on a dollar-for-dollar basis into community services for those individuals who are clearly ready to live in the community.

Chairman HEINZ. You are talking about the section 2176 waiver authority?

Dr. HOWSE. Yes.

Chairman HEINZ. I am going to inquire about that in a minute because that is quite an interesting proposition. And the Secretary had a few comments he made about that, and I want to ask about those.

But to what extent has deinstitutionalization been driven by court decisions since it does cost the State more?

Dr. HOWSE. I think that, Senator, is rather exclusively related to Pennhurst, and clearly in the case of Pennhurst, most of the individuals out of that facility have been driven by the numbers contained in the court orders. But Pennhurst aside, the figures that Secretary Cohen gave you, that is the movement of the population from roughly 12,000 to 6,800 since 1970, that goes well beyond the Pennhurst issue.

Chairman HEINZ. Did the impact of the Pennhurst decision, although it only apparently applied directly to Pennhurst, have, if you will, moral application to other institutions? Do you want to answer that, Mr. Secretary?

Secretary COHEN. I think that here in Pennsylvania, and again what Dr. Howse indicated is probably true in terms of the history over the past 4 years. My comments would be more as an observer at that time, and now as a policy setter for the future.

I think that there is a lot of resistance, both administratively and legislatively in Pennsylvania, to the Pennhurst orders. There was a lot of litigation back and forth on the question of the appointment of a master, on issues of funding, and in responding to the recommendations of the master.

The master has been before the U.S. Supreme Court twice; in fact, we expect there will be a decision today on the latest February argument before the Court.

I would not say that the movement within the Department of Public Welfare and within the State administration to decrease the population and close the three centers that have already been closed is prompted by Judge Broderick. I will put it as bluntly as possible.

But I think that it is a recognition of advancement in care.

I have had the opportunity thus far, to visit personally, four of our five largest centers. And it is probably for me one of the most exciting experiences I have ever had because I have met people there—I met a woman at Pennhurst, in fact, when I was there on Friday, who is 77 years old. And when she was 75, 2 years ago, was the first time that she was able to stand up.

She cannot really walk, but the institution on an individual basis makes different kinds of wheelchairs, and different kinds of appli-

ances, that will fit the individual clients and assist them in maximizing their individual capability.

To meet with the staff there, the occupational therapists and the personal care staff, and hear what they have done and what efforts they have made in that setting is, I think, to indicate what we have accomplished, if you will, in this country. What the people who are in the forefront of the development of maximum care and maximum services and assistance to the mentally retarded, what they have been able to accomplish just by deciding that they are going to try to do it, that it is possible.

And to have that experience, to see [illegible] at the age of 77, having stood for the first time at the age of 75, I think, is to show that we are developing in this country the capability to move people out of institutions, to have a less restrictive setting, and to help people become as highly developed as they individually can.

And just to talk to some of the people who have been in the system for 15, 20 years and what it was like then. That is not in response to a court order. The court order is responsive to, I think, the development of the capability in the profession to be able to help people become citizens in the community, or become more functional than was ever thought possible.

And there have been some problems with the court order in terms of individual clients, and the feelings of the parents of those clients and the movements of some of those clients out of the ICF/MR facility against the wishes of some of the individuals into community living arrangements.

Chairman HEINZ. I want to get into the subject in greater depth with our next panel, but as the Commonwealth's principal officer in this area, I would not want to miss the opportunity to ask you the extent to which you think the professionals involved with making decisions on who should be deinstitutionalized, are 100, or 90 percent or fully accurate, to what extent they make mistakes, to what extent they are limited by the state of the art in always making the right decision.

What would be your view as to the batting average of the decisions made by the professionals involved, recognizing that nobody is ever perfect?

Secretary COHEN. I think that is the most important qualifier—nobody is ever perfect. And there are, too frequently I think, public officials who try to say, that whatever they do or whatever they say is right, and everybody else is wrong. And if they make a decision, that is the right decision.

On an individual client basis, I think that the decisions overwhelmingly are right because they are not decisions that are made after observing a client for a couple of hours, or a few days, or a few weeks, or even a few months.

What I guess I have learned is that in many instances an individual's progress and development of capability—for example, to be able to feed oneself—that sometimes comes not from close daily work over a period of a few months, but over a period of a few years.

Time has a different meaning in this setting. The judgment that is made is made by people who have known the clients in the

center, usually for years, if not decades. I think that sometimes those decisions are wrong, but overwhelmingly they are correct.

When they are wrong, they are reversible. The serious question, and difficult question to handle, is the role of the parent vis-a-vis the role of the professional. I must say I have not really come to grips with how to do that. There has to be a balancing of the feeling of the parent, the concerns of the parent, which is often, "what will happen to my child," who is an adult frequently at that point, but still to the parents, they are a child. Parents ask the question—"What will happen after I am gone, with my child in a community facility with a couple of other people?"

There is no track record of length of time like there is with some of the centers. And that is an issue that many people are very concerned about, that we are concerned about. It exists now in a number of instances, but I think again the overwhelming number of cases, even where there has been some concern or even objection from a parent, once a person has been able to be in a community living arrangement for just a few months, it has been clear that the decision was a good one. And it has been accepted by the parents, even where initially rejected; not in all cases, but I think in most cases.

Chairman HEINZ. Is the State of Pennsylvania developing some more formal methods of accommodating parental consent, parental concerns?

Secretary COHEN. We are trying to. It is probably not an issue that can be dealt with with a directive or a policy. It is an issue that I think has to be handled by a higher sensitivity on the part of the decisionmakers.

But the state of the art has progressed to the point where there are some excellent, committed, talented professionals whose opinion also has to be given great weight.

Chairman HEINZ. You clearly, though, either have developed or are developing not an obiter dictum, but a process for accommodating the concerns of parents, and in effect, trying to meet what would otherwise be called a question of parental consent.

Can you describe that process or is it premature to do so?

Secretary COHEN. I think that what Dr. Howse has described is what process is used right now, and I do not really know what kind of change we need to make in that process, but I do know from what complaints that we have had, that we have to look at that.

Chairman HEINZ. Let us maybe come back to that if we have time.

I want to ask you about the waiver authority question, because as you are well aware, the waiver authority is somewhat new. We first put it into law in 1981. It was amended in 1982.

And the language of the law includes, among other things, the following admonition to the Secretary, which is found in section (c)(2)(d), which says, in effect, that under any waiver that you would get, that the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals, does not exceed the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for

such individuals, if the waiver had not been granted, et cetera, et cetera.

Now, you mentioned in your statement, and expressed concern about the fact that there were new draft regulations, that I gathered, would make States responsible for anything over and above what the State reasonably estimated it would have spent on this.

Given the law as I read it, why is that a bad regulation?

Secretary COHEN. I think I would interpret the law to give us the flexibility to project the cost that is not there, the savings, based upon real expenditures during the period of time in which the waiver is in effect, so that we would not have to be basing our estimates on just the best available information at the time of filling out the waiver form, without taking into account what might happen in the coming year, which would be something that can be done at the end of that period of time by looking at what the actual true costs were, either in the facility itself, from which the individual came, or in the system itself.

I am not quite sure what that standard is, but it ties the State to an estimate made in advance of the actual expenditure of any of the dollars.

Chairman HEINZ. If the HHS regulations were amended to say that a State's estimates could be adjusted for their actual experience with respect to institutional care during the period of estimating, then I think that you would not have an objection to the kind of regulation that is involved here.

You are just saying there is some uncertainty, and we do not know whether the inflation rates are going to go up or down.

Do I understand your point correctly? With that kind of experience, you would have no objection?

Secretary COHEN. That is correct.

Chairman HEINZ. You do not object to the idea that we, in Congress, do not want to spend more money than we are spending.

Secretary COHEN. No; I did not mean to indicate that.

Chairman HEINZ. You just do not want to be stuck because you might have misestimated.

Secretary COHEN. That is correct. And also, in addition to inflation, I would assume it would also be what the true cost is on a per diem basis, which could vary, depending on how many people are able to be waived out of an institution, depending on how broad the waiver process is in the State.

Chairman HEINZ. I think that is a tough issue. As you reduce the number of people in institutions because there are fixed costs associated with them, your per diem is going to rise and may create, at least from the standpoint of the Federal legislators, a false picture of what the per diem is.

Even to you it is a real per diem. It is nonetheless variable upward depending on the deinstitutionalization efforts. And the more successful you are in deinstitutionalizing, until you actually close an individual institution, you actually incur a higher per diem per person.

Secretary COHEN. But I think there is a strong incentive, because of the amount of State dollars still involved, a strong incentive to be responsible in closing institutions where you have too many.

And the closing of the three institutions in Pennsylvania, I think, comes from that incentive and not from a Federal incentive.

Chairman HEINZ. Other than that problem with the waiver authority, you mentioned the amount of paperwork. I think you said there were some 22 pounds of documentation that had to accompany, was it one or——

Secretary COHEN. That was one, to fill out the waivers.

Chairman HEINZ. What was 22 pounds? What do you have to generate?

Secretary COHEN. Senator, I did not read it myself.

Chairman HEINZ. I am sure nobody in Washington, D.C., read it. Is it patient records of all the people in that class? I mean, 22 pounds, that is like my briefcase at night.

Dr. HOWSE. Senator, it is copies of State regulations, numbers of computer printouts on the number of MA recipients by several different fiscal years, budget documents, and so forth.

And it did indeed weigh 22 pounds.

Chairman HEINZ. It sounds like most of that information is generated by a computer someplace anyway, but that does not mean it is useful, obviously.

Dr. HOWSE. Correct.

Chairman HEINZ. Is the amount of information requested, apart from the fact that it weighs an excessive amount, an excessive amount of information?

Secretary COHEN. I guess it is perhaps our feeling, as you stated, that nobody really is going through all of that anyhow, and we send it down because it is what is required. What we would like to see—and the point of that is to see—that perhaps a system could be developed where we do not have to ask permission for exceptions, because there is also some concern, and a very real concern from our appropriations people and our budget people, that the waiver system could be ended.

It is not necessarily a part of the system. It is a permission granted to waive regulations that otherwise would be in force, and that permission, as granted, can also be at a future time rejected. Then we would face a serious financial, fiscal situation in Pennsylvania, or any State would, if they had waived out of institutions with Federal dollars still coming in, a large number of people, and then subsequently found out that we will have to pay for that with just State money.

So we are looking at a policy that would, in fact, positively indicate that the Congress wants to move the country toward permanent waivers, if you will, toward the community living arrangements.

Chairman HEINZ. I think that is accurate. I think, as you can tell from the way the amendment to the 1981 law was worded, there is concern, because Congress has been burned in this area on many previous occasions. When you create, as in effect we did, an entitlement to community care, albeit through a waiver system, we have a tough time controlling costs. As you know, entitlements have a track record of ending up being much more expensive than anybody had any idea they would be.

Do you know what we are supposed to be spending, according to 1965 estimates on medicare, this year? $6 billion. We are spending $60 billion on medicare this year.

That was all people thought it was going to cost 18 years ago.

Now, you can say, what did they know back then? The answer is, not enough. Maybe it was a good thing we did not know enough. We probably would not have enacted medicare. But there is great concern that in entitlement programs, the need for a Federal budget is alive.

Are you experiencing any problems under the use of the waiver authority? That is to say, when people are deinstitutionalized into community living arrangements, what are the quality assurance mechanisms that protect people in these community-based programs?

Dr. HOWSE. Senator, the system of quality assurance that we have put into place is the same system that is used for the current community placement; in other words, the public welfare department has an obligation to inspect and license these facilities, which we will do for placements financed under the waiver.

In the case of those waiver placements connected with Pennhurst, we have a special inspection capability that is run by the department of welfare, office of mental retardation. And beyond what the State does, the county administrator has a direct line responsibility on a day-to-day basis to case-manage and to inspect for quality in the community services.

Chairman HEINZ. On the latter point, the form I would take is how you assure the institutions are properly staffed and run, the service providers are properly qualified, and so forth. Are you saying that there is, in your judgment, a good case management system to assure that someone does not fall through the cracks and does not get an inappropriate mix of services?

Dr. HOWSE. Senator, I think, on balance, there is a good case management system in place in the counties. There are still problems. People do fall through the cracks in Pennsylvania, both because of lack of good case management and also because of lack of revenue in some cases, and some of the priorities that get set.

But I think, on balance, the counties have done a responsible job of case management.

Chairman HEINZ. From my own perspective, things are getting better. One of my first experiences was when I became a Member of the House in 1971. It was about 1 year later when a severely mentally ill young man literally fell between the cracks in the community mental health-mental retardation system in the county. He was sent from one center to another, and because he moved, his family moved, or some reason like that, when he showed up at another center, they did not know what to do with him. They told him to come back later. He ended up committing suicide. This person was in need of a considerable amount of assistance.

We put together a community task force of volunteers and professionals, had them look at what was going on in the system in Allegheny County. The very fact that there was a concerned group of about a dozen people, including psychiatrists and community leaders, looking over the shoulder of the county, caused the county

just by that very oversight function to substantially improve what it was doing.

We found that it really helped; it really worked without having to issue press releases and write new laws; just a little community attention of the right kind can go a long way to improving what local government is trying to do.

Mr. Secretary, I have no more questions for you. I think you have given us some very helpful testimony, particularly on some of the things that the Federal Government does to you, as well as what we could do for you.

Secretary COHEN. Thank you.

Chairman HEINZ. Our next panel consists of John Swain, David Eisenberg, and Richard Browdie.

Gentlemen, will you please come forward and join us. I would like Mr. Swain, who is in the middle of this distinguished group of witnesses, to be our leadoff witness. Mr. Swain, I understand that you are a family member, or the son of a client, who is served by the Philadelphia channeling demonstration project.

And I understand that you are going to tell us a bit about your family member's experience in that regard. Is that correct?

Mr. SWAIN. Yes.

Chairman HEINZ. Please pull up a microphone and proceed.

STATEMENT OF JOHN SWAIN, PHILADELPHIA, PA.

Mr. SWAIN. Senator Heinz, I would like to share with you the reflections of home care for my mother, Elizabeth Hannah. My mother, Elizabeth Hannah, resided in Philadelphia, Pa., until she expired on June 7. She was more than 90 years of age.

She was of strong will and determination. Even though her health began to fail several years ago, it was not until June 23, 1982, that she became totally homebound and bedridden. She had four separate attacks, each time being admitted to the hospital.

I began to become more concerned of what shall I do with and about mom when she would come home from the hospital. Fortunately, the director of the Southwest Enrichment Center, a senior citizens organization in the block where we reside, was instrumental in helping, with contact of medicare services.

I was informed that medicare home care services was very limited and short term. I was also concerned about my employment, help from our friends, the neighbors, and church members.

I realized that any free help is limited and undependable because many people work or have their own personal problems.

This search for help for mom continued until one of our church members, and a trustee of our church, suggested that I contact the case manager of the channeling project, Mr. Skirvin. His aunt had been serviced through this organization.

After the necessary visits and inquiries, Mr. Skirvin informed me that mom would be accepted into the channeling project; thus began the home care service provided by Bayada Nursing under the direction of the channeling project.

I am more than sure my mother's life was prolonged, for she was more comfortable at home than she would have been anywhere else. The idea of being home in her own bedroom, looking out from

the window and seeing the faces of her neighbors, watching them clean their porches, sweep the sidewalks, and other little things, kept her alert and interested in life.

Having lived in this community for more than 70 years was a total part of mom's life.

There are many, many elderly people connected with our neighborhood and church who need the same kind of services and care of which my mother received. Mom had been a member of the Monumental Baptist Church since 1912, and for her church members to come and yell upstairs, Mom Hannah, I am coming up, was another job that she would not have received on a regular basis.

Even though much help was received from channeling project, our friends, neighbors, relatives, and church members, there were added expenses that had to be met that I did not anticipate. Almost all household expenses increased, and most of them doubled.

Whenever my mother was in the hospital, most of the time without warning, the hospital personnel would announce that I may take my mother home the next day. This was very disturbing to me. Most of the time I was not prepared to receive her at home, for I had not had time to arrange home care for her.

It was not only disturbing to me, but upsetting to mom. And she finally stated that she did not want to go to another hospital again, and not to mention a nursing home to her.

The day-to-day personal care provided by the ladies from the agency was the best. My mother was always clean and well-cared for by all who attended her. She was happy to be home and cared for, and would often say, "I am so glad to be home in my own bed and not in some hospital or home."

The electric bed, water mattress, commode, the geriatric care, and other items for her, helped to combat bed sores and many other problems that plagued my mom's sick body.

The visits by the nurses, and their reports to our family physician, helped in keeping a close check on mom's condition.

My job took me to Florida periodically. However, my employers, Mr. and Mrs. Irving Weinstein, were very, very understanding and considerate people, and were most supportive of our situation.

From time to time, with the proper care that she received, mom would show signs of improvement. There were no visiting restrictions; therefore, people from the church, friends, and neighbors would come at their own convenience to visit, and keep in touch, a part of the everyday world she enjoyed.

She also had a telephone by her side. And I might add that her telephone was busier, if I might use this expression, yes, busier than the White House phones. Someone was always calling her at all hours just to chat, and she delighted in talking.

Mom also read the newspaper daily until just a short time before her passing; this is something, I am sure, she would never have been interested in doing had she been in a hospital or a nursing home.

At home and in her own room mom felt that she was still in control of things. From time to time she would yell to someone, close that bathroom door, or who is in my kitchen, or honey, do not move anything from my dresser. In other words, she was still a total part of the world, although she was bedridden.

I am certain, without a shadow of a doubt, mom would not have lived as long as she did had she been in another setting. And it is organizations, such as channeling project that prolonged her life, and yet made her happy as well as comfortable.

One of my elderly neighbors, Hattie Williams, recently complimented me and my family on how well mom was cared for and loved during her 1 year of being bedridden at home, and then announced that she must give up her home of more than 40 years, at the age of 90 years, because she can no longer care for herself.

She has to; she must go into a home. And, of course, she is most disturbed and upset over this matter.

If I have any regrets, it is that more senior citizens cannot enjoy the service extended mom during her last days and that the hours of channeling project could not be extended to those in need.

I might close by saying that on the day before mom passed, the nurse from channeling project, in her expertise, noticed a change in mom's condition and notified our family doctor, who in turn made arrangements to have her taken by ambulance to the hospital the next day at 11 a.m.

Mom heard this and knew this; however, she never complained or discussed it as she normally would. However, I thought about the fact that she had told us she would never leave home to go to the hospital again, and the only way she would leave would be in death.

It was ironic that before the ambulance could arrive the next morning, mom gave up the will to live, and the rescue squad had to be called. They worked faithfully, but mom would not respond. It was then that mom left her home of more than 70 years, but in death, instead of going to the hospital.

I am still rejoicing to know that every base was touched to keep her comfortable and her wishes and desires granted, before she passed. I was home from Florida in the morning of her passing; therefore, I witnessed all of the above, and can only say, thanks to channeling project and Mr. Skirvin for their service and care to mom and helping to prolong mom's life.

Chairman HEINZ. Mr. Swain, that is a beautiful introduction for Dr. Eisenberg, who is our next witness. He is the director of the channeling project that served you and your mother, apparently so well, at least by your most eloquent testimony. And it is my understanding that in addition to being director of the Philadelphia channeling demonstration project, Dr. Eisenberg has quite a distinguished track record.

He was previously assistant administrator for the Kendall Crosslands, Quaker Life Care Facility. And he has served as a research assistant to the Philadelphia Geriatrics Center.

He has done extensive work in developing a case management system for the Philadelphia Area Institute on Aging. He is a Ph. D. kind of doctor, and not an M.D. doctor. And he has done some social work and social research. He has a master's degree in social planning from Bryn Mawr College.

Dr. Eisenberg, my immediate impression is that there is nothing you can add to what Mr. Swain has said about your project, but we want you to try anyway.

STATEMENT OF DAVID M. EISENBERG, PH. D., DIRECTOR, PHILADELPHIA, PA., CHANNELING PROJECT

Mr. EISENBERG. I will do my best, Senator.

The national long-term care channeling demonstration was mandated by Congress in 1980 with, as you know, bipartisan support, to examine the viability of in-home, long-term care to frail older persons who are at risk of institutionalization.

It is a field experiment, and is serving and studying a group of over 6,400 older Americans. The demonstration will study three major outcome variables: The well-being of those participating, service utilization, and the cost of in-home, long-term care.

The term "channeling" refers to a highly structured case management process by which older persons needing long-term care are carefully assessed and assisted with their families in planning for their care.

This process takes into consideration all viable options for care and all potential caregivers, including family, friends, and voluntary organizations.

Project clients have a case manager assigned to them. This case manager completes a formal assessment of their clients' functioning and health; designs with the client and family a detailed care plan; arranges for needed services; monitors the adequacy and appropriateness of service; and periodically reassesses each client's condition and need for service.

The 10 sites are divided into two groups—basic sites and complex sites. Basic site staff provide case management alone to their clients. Complex sites provide case management and have the added capacity to purchase health and social services on behalf of their clients.

The Philadelphia channeling project is a complex site. Our staff of 10 case managers serve a caseload of 500 older Philadelphians. We are able to spend up to 60 percent of the cost of a medical assistance reimbursed nursing home bed for in-home services for each of our clients.

Each case manager directly controls the type, amount, scope, duration, and pattern of delivery of a dozen different services which his clients may need, which are covered under the demonstration, including such services as nursing, homemaker, home-delivered meals.

Case managers can allocate funds between clients according to need. Thus, they have a powerful incentive to be prudent purchasers and prudent users of service in order to have resources available for one of their clients who may experience a temporary need for a high level of care.

The demonstration's data will not be analyzed until 1985; nevertheless, site staff and government project officers have noticed striking similarities among sites. First, the need for case management is high. Older people and their families have a tremendously difficult time wending their way through the maze of service providers and decisions. They need good counsel on making decisions, like when to choose nursing home care.

Second, custodial care for older persons at home is either in short supply or is unavailable.

Third, there is a uniformly high desire among older people and their families to avoid institutionalization as a solution for needed care, unless absolutely necessary.

Fourth, the services that clients need the most seem to be in shortest supply. Over 90 percent of our clients in Philadelphia—and this is true in the other sites—are receiving homemaker service. Almost 60 percent have needed evaluation and ongoing service by our community nurses.

Our biggest expenditure by far is for basic personal care and housekeeping, not some fancy, esoteric professional service.

Fifth, our expenditures for services which we control are less than what we expected to spend. All five complex sites are spending less than half of the funds available.

Sixth, we never cease to be amazed by the level of need for service, the number of extremely frail and ill older persons residing at home, and the high level of support provided by families. Between 10 and 25 percent of our clients, depending on which caseload you look at, are totally bedbound and require total care.

They are unable to perform even the simplest self-care tasks, like feeding themselves. Families and friends work valiantly, but in our experience, cannot weather the level and constancy of support needed by their older charges by themselves without doing damage to themselves.

The title of this hearing is, "Community Alternatives to Institutional Care." The term "alternatives" is a misnomer when overused. One needs only to provide in-home, long-term care for a few short months to recognize the importance of nursing homes.

When we need a bed, nothing else will do. We are not discussing here a zero sum redistribution of long-term-care dollars from nursing home beds to community-based care. Rather, we are facing the choice of increasing or decreasing the expansion of funds to serve the ever-rising population of very old Americans, the group most likely to need high levels of long-term care.

Investing in community-based care may slow the per capita growth of expenditure for long-term care. More people will be served for the same dollars.

In closing, I would like to divulge a secret of the demonstration, not one that is intentionally held, but a little known fact nonetheless. Delivering high quality community care requires no act of magic, and is not either extraordinarily complex or highly technical.

Many communities already have the pieces necessary to forge a delivery system. What is missing, in our experience, are the resources, and a level of resources and a unifying structure which is not dominated by providers, and which is skillful enough to case manage with the right incentives to prudently purchase and use services.

Senator Heinz, my staff, and I, and our 510 clients, continue to appreciate your interest and your leadership in addressing this national problem.

Chairman HEINZ. Dr. Eisenberg, thank you very much. And I must say, judged by many comments, including those of people like Mr. Swain, we should be complimenting you on running a good

demonstration project. I will have some questions about that at the appropriate time.

Our third member of the panel is Richard Browdie. He is the deputy director of the Philadelphia Corporation on Aging and represents, among other things, the Pennsylvania Association of Area Agency on Aging Directors. And I might add that I feel I have made a small contribution to his advancement in that cause, because one of the previous people who held that title, is a young fellow named Mike Rodgers. After Mike went to the Department of Aging, just to make sure that he would be out of harm's way, I hired him on the staff of the Committee on Aging.

And Richard, I congratulate you, and I sympathize with you.

Mr. BROWDIE. Thank you, Senator.

I will let that part pass.

Chairman HEINZ. I think you would be well-advised to do so. Please proceed with your testimony.

STATEMENT OF RICHARD BROWDIE, DEPUTY DIRECTOR, PHILADELPHIA, PA., CORPORATION ON AGING, REPRESENTING THE PENNSYLVANIA ASSOCIATION OF AREA AGENCY ON AGING DIRECTORS

Mr. BROWDIE. Given the time constraints we have today, I would like to briefly make several points relating to what seems to me to be the most important lesson we have learned from our experience with the channeling demonstration, and with other long-term care activities.

These points will, I hope, be useful in thinking about a national policy relating to the development of alternatives to institutionalization for the chronically impaired.

The first point is that this is clearly a problem of national scope and scale. Therefore, there is a legitimate and even compelling need for national policy development and administrative intervention.

You, Senator Heinz, and other members of the Special Committee are to be congratulated on your willingness to provide leadership in an era when the politically popular and easy thing to do is to devolve national responsibilities to States and municipalities.

There is no rationale that I can think of that says that an older person, a frail person, or a chronically impaired middle-aged adult, for that matter, should have to have unequal opportunities to find humane and sufficient care anywhere in this country.

My second point is, however, that national policy should stipulate that States will indeed administer programs through local or regional entities of whatever type are suitable to the political, geographic, and demographic character of the area.

Nationally operated systems seem best suited to financial matters where standardization is appropriate and necessary. Long-term care requires flexibility and knowledge of the eccentricities of each community where clients live. In short, national policy should describe what will be done. State policy should establish organizing principles, standards for performance, and quality control measures.

Local managers should have the flexibility to operate the system, focusing on the interaction between clients and providers in developing service patterns that reflect local realities.

Without oversight, however, local quality cannot be assured.

Third, deferring or preventing institutionalization for older persons is a function of the actual existence and availability of service alternatives. Therefore, cost containment cannot occur until the alternatives exist. The belief that this is necessary to save money in the long run has motivated the Pennsylvania Association of Area Agency on Aging Directors to develop proposals for community-based, long-term care for the elderly financed by the Pennsylvania lottery.

A bill based on these proposals was introduced in the House last week. But before we get too satisfied with ourselves, I should point out that it is because of a lack of national policy that this initiative was undertaken. And the argument can be made that the lottery was developed for discretionary benefits; so that it should not be counted on for life-sustaining systems of care that should exist everywhere.

Fourth, a system of alternatives to institutionalization cannot function effectively without some sort of interrelationship with long-term care institutions. It is absolutely clear that some people need nursing homes. And when you need one, nothing else will provide care as comprehensively and efficiently. Even if locally managed systems do not manage the consumption of nursing home beds beyond some preadmission assessment function, which is necessary to assure that people do not consume resources excessively if they do not have to, at least some form of relationship has to be established to permit clients to move between community care options and nursing homes when it is necessary and appropriate.

The key to the system is to use appropriate alternatives at the appropriate time. The necessary continuum of appropriate alternatives includes nursing homes. It does not exist only outside of them.

My last point is that we have found the role of the local management agency as prudent purchaser to be the most important feature of the whole system from the point of view of identifying and capturing cost savings. The real issue is that in a free market system, a provider of care that also identifies his patients and sets his prices has put himself in the enviable position of being his own gatekeeper.

This is the case with the medicare system now. With regard to protecting the public's purse, the conflict of interest is clear. A provider's incentive is to maximize revenue and minimize costs.

Even an HMO with a capitated payment has an inverse incentive to take in members who are least likely to be ill, while at the same time, keeping up payment flows to their various units to justify their rates.

In the channeling project, we have an agency which manages consumption on behalf of the client. We are in a bind between proving our efficiency by staying within our budget per client and assuring adequate care to meet our heartfelt wish to serve and advocate for the client.

Someone has to manage that conflict, and since we provide no hard service directly, we have no practitioners, employees, managers, or stockholders who will measure us on how much revenue we generate for any particular service.

This is an extension of the principle that area agencies on aging should not provide direct service that is an underpinning of the Older Americans Act. Although assessment, case management, and client monitoring are really extensions of the management function and need to be a part of the direct activities of the long-term care agency of the future.

If a company were going to build a large building, it probably would try to find a general contractor who was being paid only to protect its interest in dealing with the various firms doing the actual work.

This removal of vested interests is critical to developing a system where cost savings do not have to sacrifice concern for adequate care on behalf of the client, and quality of care cannot be used as a way to justify exorbitant reimbursements.

In the interest of our schedule for the hearing today, I will close here. I will be glad to answer questions you may have now and also to answer them for purposes of the record.

Thank you again for the opportunity to appear before the committee.

Chairman HEINZ. Mr. Browdie, thank you very much. And I will have some questions for you.

Let me return to Mr. Swain. Mr. Swain, first of all, again let me thank you for a truly eloquent presentation. It is my experience that to hear an individual such as yourself provide a real case history, and with no disrespect to all the others so knowledgeable, is worth, at times, a dozen of even the most expert witnesses.

Let me ask you what would have happened to your mother and what you would have done if the kind of services that were made available to you through the channeling alternative had not been available?

Would you have had to change your employment situation?

Mr. SWAIN. Well, I am sure I would have had to make a number of adjustments, which I did anyway. I was given permission to go to my job a couple hours later, to just sort of get things started in the morning with my mother, where she was concerned

And had I not had the help of channeling project, I am sure there would have been even more changes than that. I really do not know just where I would have gone, because I was not in a position to stop working, stay home, and take care of my mother.

And it would have become a very difficult problem to handle, I mean, suddenly, because she was stricken suddenly. And it would have taken time to organize myself to the point where there was someone to help, because even though she had two elderly sisters, they were not available. They were in Asbury Park, and they were not well enough themselves to help.

So I would have had to make a great deal of readjustments. Luckily, as I stated in my remarks, I had a lot of friends, for which I always will be grateful, and very, very fine neighbors, and very fine church members who offered free help occasionally.

But that can only last so long. People are with you for an immediate emergency. But when it stretches out for a long time, as I said, they have things to do by themselves and they cannot.

So I would have had to make some sort of readjustment somewhere along the line.

Chairman HEINZ. Thinking about the services provided to you by the channeling project, what are the most important, most vital of those services?

Mr. SWAIN. So much of it, all of it was very good. But I suppose what helped a great deal, with my having to go to work in a job every day, was having the people from the agency to come in, furnished by the channeling project, to come in and help get my mother started in the morning, get her breakfast, and out of bed, onto the commode, and back to bed, and do things like that to help to get her day started, which gave me a chance to do things that had to be done to keep the house going, and prepare myself for going to my job.

And by that time, later in the day, it was possible for me to make arrangements to have friends come, or relatives come, or someone else who would come in later in the afternoon and take over, being in the house with her after the people from the agency would leave.

So I just had to work. The assistance and the help the channeling project rendered for us, I had to try to build my life around it.

Chairman HEINZ. That sounds like it necessitated some pretty clear communication between you and the people of the channeling project.

What was the nature of your relationship with them? Did you sit down together and plan out what you could do, and what they could do? How did it work?

Mr. SWAIN. Yes. When I first received a visit from Mr. Skirvin, the caseworker, and he stated to me just about what would be provided by the channeling project, and what to expect of them in the way of hours per day that would be provided by the agency.

And he wanted to know what could I do. And I, of course, told him, tell me whatever the project would provide in the way of time and services, and I would have to build the rest of my mother, and my life, around it.

So, once he established what I was—the nurses, the home care ladies, would arrive and what time they would leave, then that meant that I had to pick up the slack of the other times. And fortunately, I was able to provide it. The only time it was any problem is when I was out of town because of my job, as I said, took me to Florida 2 or 3 weeks out of every 6 weeks, or something.

And when I was in town, of course, there was no problem because I was home at night myself. And there was just from the time the ladies from the agency would leave in the afternoon until I returned at night. Or when I was out of town, it meant getting someone to stay all night, because a person completely bedridden cannot be left in a house alone.

Chairman HEINZ. What kinds of costs did you have to bear?

Mr. SWAIN. Well, as I stated, I did not have any private insurance. Meager earnings of my own, and what very little my mother had with social security, and what not. We managed to get the

services of a couple of friends, young ladies who were unemployed at the time, who would come and more or less babysit, you might say, in the afternoon after the other ladies left.

My lady friend would come and help, and there were neighbors who would volunteer. But the costs that I had to put in was giving some little donation to these ladies who came every day. I finally secured the services of two ladies who were not doing anything, and they had had a little bit of nursing care experience, but they were not working for an agency.

And they were going to school part time, and they agreed to come in in the afternoon and stay with my mother. And when I was away, they would stay in the afternoon and all night.

Chairman HEINZ. Were there any other costs to you that you had to bear? Did you have to purchase any equipment? Were there any fees or copayments you had to make to the channeling project?

Mr. SWAIN. Well, the first few months, quite a few months of my mother's illness, one of the heaviest expenses that we had was providing—she was completely incontinent—so she had to be provided bedpads. And at the time when I would go away, I would have to purchase anywhere from $75 to $100 worth of boxes of pads to be sure there was enough sufficient there for the ladies to use when I was away.

That, along with, as I said, the other expenses in the household increased, because of the electric bed created more—I know we had to have it, and things of that sort, but the medicine was taken care of by some one of the agencies, DPA agency.

Chairman HEINZ. Have you any idea what all of those costs might have run you on a weekly or a monthly basis, even with this kind of help from the channeling project?

Mr. SWAIN. You mean what they added up to?

Chairman HEINZ. Yes. A week, or a month, or per year.

Mr. SWAIN. Well, at the point I was donating at least $150 to the two ladies that were helping, not each. I could not afford that.

Chairman HEINZ. $150 a week for some day care services on a semiprofessional basis?

Mr. SWAIN. Yes.

Chairman HEINZ. And, then what, $10, $15, or $20, for equipment, bedpads, and the like?

Mr. SWAIN. Yes, with the bedpads especially. And there were many things that I had to take care of.

Chairman HEINZ. So that would have run you well over $5,000 a year?

Mr. SWAIN. Oh, by all means.

Chairman HEINZ. And without that kind of expenditure, your mother could not have made it at home?

Mr. SWAIN. No, she could not.

Chairman HEINZ. And you have testified very beautifully as to how much she enjoyed being at home, and how meaningful it was to her to have the many others around.

Mr. SWAIN. It meant a great deal.

Chairman HEINZ. Let me ask the man who runs the project, should we wait until 1985 to expand this concept?

Mr. EISENBERG. The research is a dispassionate enterprise that relies on data for conclusions. That is not to say that we, at the site

level serving older persons, as we do, are dispassionate about this. We have very strong feelings about this.

And that what is currently a matter of fate, which is that in-home, long-term care, will be economically viable as well as good for older persons, is going to be borne out by the data. It takes some time to get—I guess we spent about a year planning for this project.

So I would have to say, on the basis of our impressions, our strong impressions and common impressions across the sites, that it would bode well to start planning for this kind of enterprise now.

Chairman HEINZ. I gather the most important component of making this work, since a number of people, including yourself, have pointed out that in most communities, at least a good part of the services that would otherwise be needed, do exist as a case management system.

You put a lot of emphasis on that in your statement. There are a number of critical elements to making that system work, not the least of which is having good people. But what is the key to making sure that those good people, assuming that they are available, do the kind of job that is needed?

What makes or breaks their ability to function well?

Mr. EISENBERG. The long-term care, like other human services, is intensely labor intensive. And the quality of the performance of the worker is a direct result not only of the administrative structure, but also incentives that they have as individuals. It is not reasonable to expect a worker, a case manager without adequate resources, to draw on, to be able to do the task of case management very well. You need something to manage.

I am sure there is a place for good counsel. But under the demonstration, our workers are actually responsible for allocating services on behalf of their clients.

Chairman HEINZ. Do you give them a services budget that they have to decide how to allocate?

Mr. EISENBERG. That is exactly right, Senator. As they detail a care plan, sitting down in the living room or kitchen, often of the older person's home, with a family member or two, they detail a care plan.

And then back in the office, they actually cost out precisely what the care plan is going to entail in terms of dollars. We have a very straightforward microcomputer, which even social workers feel comfortable with, in the office, that weekly, as social workers and the case managers go into supervision, details how much the care for each client costs, and then the cost in aggregate for their caseload. So case managers are not only directly responsible with real authority, they are also highly accountable.

Their supervisor can see patterns of expenditures and also compare different workers' use of resources.

Chairman HEINZ. How many cases are assigned per case manager?

Mr. EISENBERG. The maximum under the demonstration is 50. And I am glad you asked because like resources, I think that is another critical variable. I have seen programs where case managers have 100 cases. It is not uncommon for a worker to say, I have 100 people whom I am assigned.

But it is not possible to get blood out of a stone. When a case manager says that they have 100 cases, they really have 40 cases and 60 sitting in the files somewhere. It is just not possible to manage some of the unreasonable sizes of cases that we have seen in the past.

Chairman HEINZ. What is the average caseload per caseworker?

Mr. EISENBERG. As of last week, we are now up to 50 cases per worker. We are at maximum.

Chairman HEINZ. Is that a feasible average? Even though you have indicated it is a maximum, is it a feasible average?

Mr. EISENBERG. Our experience is with adequate support, meaning supervision and clerical support, it is feasible.

Chairman HEINZ. Do you have certain specialized tools for client assessment that are unique to the project?

Mr. EISENBERG. We do.

Chairman HEINZ. How important are those tools to your success?

Mr. EISENBERG. There are two tools that the demonstration uses. One tool, in fact, the shortest of the two, but in some ways the most important, is a screening instrument, which, over the telephone, in a half hour contact with a referring professional and an older person interested in the project, the screening instrument makes the decision as to whether this older person is in need of in-home, long-term care.

That tool is quite important because if in-home, long-term care services are to be cost-effective, we want to make sure that we target the appropriate group for services and not create a new set of beneficiaries.

The second tool that we use, which is lengthier, which takes about an hour, and a home visit, is used by the case manager in an older person's home to assess functional deficits and problems with their environment, a constellation of maybe seven different areas in an older person's life, that together come these variables which determine whether a person could remain at home with service, or possibly should go to some kind of alternative living arrangement, or should in fact go to a nursing home.

There is a small subset of older people who, once we assess them at home, we can conclude that their needs really are too great for in-home, long-term care or the risks of them remaining at home are too great, and they really should go into a nursing home.

Chairman HEINZ. One of the things that you claim is not a secret in your demonstration is that you have a unifying structure. And it is important that it is not dominated by providers, doctors, hospital administrators, or anybody else you care to name.

What is the problem with providers?

Mr. EISENBERG. I think the problem is not with the providers, Senator. It is with incentives. All professionals tend to see problems in terms of the solutions they are most comfortable with. And so a nurse will tend to see nursing problems and nursing solutions. And a social worker, who is working in mental health, will tend to see mental health problems and mental health solutions.

The problem with having providers manage services is that it may not be their service that is the most critical one to address a problem that an older person has. So it is more a question of perspective and incentives.

A nonprovider has no stake, as Mr. Browdie pointed out, to garner resources for providing agencies.

Chairman HEINZ. You have some 500 people in this project, and then you have about 10 caseworkers. Do you supervise them yourself?

Mr. EISENBERG. No. There are three supervisors, social workers and a nurse.

Chairman HEINZ. So you have about one supervisor for every three or four caseworkers?

Mr. EISENBERG. Correct.

Chairman HEINZ. And I assume that is an important element?

Mr. EISENBERG. It is critical. It is critical to productivity, in fact.

Chairman HEINZ. Why?

Mr. EISENBERG. For one thing, not only is this task labor intensive, but workers, in order to do their jobs well, must be in the community all of the time. And so there has to be some way of managing the farm, managing the shop when our staff is in the field working with providers and working with clients.

Chairman HEINZ. How interchangeable are the supervisors and the caseworkers?

Mr. EISENBERG. They are directly interchangeable. They have all had the same training. In fact, I and my assistant have operated as case managers when we have needed to.

Chairman HEINZ. Could you change a case manager so that they function adequately as a supervisor tomorrow?

Mr. EISENBERG. I think not. I think that would be a harder switch.

Chairman HEINZ. What would be the critical difference?

Mr. EISENBERG. Experience. Experience and also a sense of mission. The supervisors are directly responsible for the productivity of the project, of all of the case managers who are their charges. We apply basic management principles to our work, like a producing organization would. And I think it would be difficult for a case manager to hold another peer responsible for productivity like a supervisor can.

Chairman HEINZ. One question I probably should have asked you at the outset is: What proportion of the 500 or so people you serve are not eligible to be enrolled in medicaid, or otherwise categorically eligible?

Mr. EISENBERG. Of our clients today, 25 percent are enrolled in the medical assistance program. All of them are enrolled by requirement of the demonstration, are enrolled in medicare part A because we are using social security trust fund moneys.

That is, of course, not to say that 25 percent of older persons are enrolled in medical assistance in the State. In fact, the figure is much lower. But we have a higher proportion.

Chairman HEINZ. For your information I am going to be introducing legislation in the next week or two that will allow the integration of two major public programs for the 4 million persons dually eligible for medicare and medicaid. This legislation would permit, where appropriate, the coordination of delivery and payment for services for this dually eligible population.

Going back to the issue before us today, GAO issued a report to the Congress in 1979, which was entitled, "Entering a Nursing

Home, Cost Implications of Medicaid and the Elderly." In that report, the GAO examined factors which lead to premature or avoidable institutional care.

One of the recommendations in their report was that some form of control over costs and utilization of community-based services must be implemented, until more information is available about the mix, amount, and cost of services which prevents institutionalization.

Is what you do an effective control over costs and utilization, or do you think GAO is looking for something and we, therefore, should look for something beyond what you do now?

Mr. EISENBERG. We have talked about this quite a bit. And if you do not mind, I would like to defer to Mr. Browdie.

Chairman HEINZ. All right. We now defer to our last panelist.

Mr. BROWDIE. Senator, actually, I think to characterize our response, we probably would say that GAO was only incorrect in saying that they only should apply such a governing system until you find out more. Our experience is that the cost per client would have to be managed as a function of the system itself, rather than as a research project.

If you look at what channeling does, it tries to make a judgment as to, over time what the cost per person will be, include that cost per person as part of the appropriateness decision in the appropriateness equation.

Without that kind of thinking being applied consistently throughout the system, in lieu of that kind of thinking, what will be established is a cost-based reimbursement system or some kind of price-fixed reimbursement system, which leaves the way open again to the providers, only incentives running, driving the system.

And what our point is, that experience has shown time and again that if you do not have someone whose incentive it is to contain costs, yet around individual circumstances, then you either have inappropriate brakes being put on services to contain costs, to arrest costs, which always winds up excluding people, or people that ought not to be excluded.

Or you wind up with a system where providers can just keep on sending you bills until you stop paying, which is ruinous in other ways.

Chairman HEINZ. The most important point that you have just reinforced, is that you want an honest broker to manage this, essentially, casework function. The network, the area agencies on aging are out there. They are all, like yourselves, competent, well-informed, outstanding people. They have proven their ability to handle case management.

Does that not argue for going national with this demonstration project?

If not, why not? If so, what problems are we going to encounter?

Mr. BROWDIE. Well, counting on the good will of those in the audience that may hear my remarks, it is not necessarily so that everybody is—not that we are all that terrific—but it is not necessarily so that the aging network is ready to take this kind of a leap. Our experience tells us that what we are really talking about is a second generation organization that develops managerial skills

and technologies that are not generally available right now, at least generally being used right now.

Chairman HEINZ. Yet those are the skills and technologies that Dave Eisenberg is using and proving out.

Mr. BROWDIE. Yes; and there have been other examples. It is not totally unique. It is just that it is also true that there has not been a general mandate to do this. However, before I sell out the network entirely, let me say this——

Chairman HEINZ. You said you wanted your present responsibility to be only a one-term job?

Mr. BROWDIE. Right. It may only be a 15-minute job. But the other issue is, though, that I would say that the aging network, it does not make sense to me, on the other hand, to go out and create an entirely new system to do something, that appears to me, to be not too much of an intellectual leap away from what the aging system was indeed designed to do and has never been actually empowered or enabled to do.

And, therefore, the second generation is really a matter of upwardly revising the skills and the capacities, rather than going out to reinvent something.

Finally, that the agency system is the closest thing that the country has; one of the things I might add, if I can, is there has been an awful lot of progress in the last 10 years in the aging services.

And one of the reasons I would submit that that has been true is the synergy that comes from having an aging network, whether that is statewide or whether that is nationwide. And that same kind of synergy can be applied to this problem, if indeed something like that is attempted.

If the Nation tried another approach and said, well, there should be something different and has no sense of national purpose, there will not be a network.

And I would suggest that the kind of progress that we have been able to make in 10 years would be a lot slower and probably will not be achieved.

Chairman HEINZ. Let me ask you the bottom line question, which I am sure you have given a fair amount of thought to. You have suddenly become the only Senator in the United States, and the Speaker of the House and you have eliminated all of the Members of the House of Representatives. All you have to do is write the legislation that you want as of today, and vote for it. It passes both the House and Senate because by virtue of a split person, you have become a unicameral legislator unto yourself.

What would you do as of today? And then would you advise me to try and do it?

Mr. BROWDIE. Fortunately, for all of us, I would say what I probably would want to do would be to pattern—first of all, this is something that the research will speak to that is not clear, at least to us, and that is the appropriate relationship in terms of eligibility.

And I am talking about low-income people. It is not clear just yet how, when the spend-down phenomenon begins to overtake the public's interest in not paying for everybody as if they were poor, for long-term care because it is just not clear to me how soon it

makes sense to start to make services generally available to people without cost.

With that caveat in mind, however, I guess I would say——

Chairman HEINZ. This demonstration program, medicaid eligible and nonmedicaid eligible, are treated alike, as I understand.

Mr. BROWDIE. That is correct. But the point of the research is to capture all relevant financial information so there will be some longitudinal sense of what the consequences might have been if there had been some distinction between the two.

With that caveat, though, I guess what I would say is that I would try to whip up for myself to vote on a national program that would manage long-term care costs through a national network based on the AAA model, although not necessarily some of the same constraints.

I would frankly require that the States would administer programs through substate organs of some sort. And I would try to stipulate what those programs would do. I would make them responsible for long-term care only. I would not make them responsible for acute-care services, because I think they are of a different nature.

And there is not enough known, and the exact relationship, and how they are done. And I think they might be different sciences and different kinds of things involved, sufficiently different that it does not make sense to patch the two together, at least at this point.

And then I would vote on it.

Chairman HEINZ. And send it to the President and keep your fingers crossed.

Mr. BROWDIE. That is right.

Chairman HEINZ. In that legislation, the details of which are not altogether clear to me—they may be to you—how would you pay for these services? Would you enact a kind of a universal medicaid waiver that takes care of 25 percent of the people?

With this additional money, can we, by virtue of some kind of miraculous good management of the noneligible, save money on what we would otherwise spend on medicare?

Mr. BROWDIE. I think the first thing I would do is set a target, anyway, as to what would be allowed to be spent. I would try to estimate what this country expects to spend without doing anything.

Chairman HEINZ. We tried to do that. We are always wrong, but we should try.

Mr. BROWDIE. Maybe we could get a little sharper and try to make that the upper limit because it does not make sense to do anything different if you are not going to be more efficient in so doing, so that the cost per person overall would have to come down as a fundamental target of the whole enterprise.

Specifically, I cannot say that—believe that the gross costs would come down sufficiently so that with no more money, all these additional people would be served. I would, however, say that I think in terms of financing in the short run, we would have to examine costs over the first 5 years or so differently than over the long haul, because I do think that the conflict in the fundamental cost

structure of providing chronic care in the country to be changing dramatically.

If people were being viewed in terms of costs of their care, regardless of where they went, and that was the financing subject that was undertaken, rather than we will do this for this kind of program, I think it might substantially change what was going on.

Chairman HEINZ. Frankly, I think you have a lot less of a problem with poor people than you do with nonpoor people. And, by the way, the distinction between poor and nonpoor may be very clear to all of us who work with this criteria, but not to the person who does not, who has not been designated medicaid eligible or food stamp eligible.

It is not clear to them that they are not poor, even if they are, by some statistical definition, middle class in this day and age.

Mr. BROWDIE. Six months in a nursing home usually qualifies them.

Chairman HEINZ. It would make just about anybody eligible for medical assistance. My point, though, is that given that two-thirds or three-quarters of our elderly population are not categorically eligible, where would the money come from for them? Right now, medicare only pays for hospitalization and a limited amount for rehabilitative therapy. Where would we get the money to help them?

Mr. BROWDIE. Assuming that other savings were not found.

Chairman HEINZ. If you can find them, I am all for it.

Mr. BROWDIE. There is a lot of research that implies that acute care is expected to drop with appropriate care options being provided. It is just that I cannot lay claim to any kind of estimate of what the consequences of this would be. And that is why I keep saying, for about 5 years or so, you probably would have to go without knowing what those charges would be.

Chairman HEINZ. Let me ask Dr. Eisenberg if he has a comment on this point. He works also with a group of people who are not eligible.

Mr. EISENBERG. The original intent of the demonstration was to track, as we look at service utilization, was to—I would like to comment on Rich's point about hospital care—was to track the difference between the people we were serving and their use of nursing home care, and the people we were not serving who are using the already existing services.

Chairman HEINZ. You have a control group, in other words?

Mr. EISENBERG. Correct. We have a national control group that, therefore, controls in Philadelphia. The thought was that with adequate community-based, long-term care, we would have some offset savings by keeping some people out of the nursing homes who would ordinarily go in.

But nursing homes in Philadelphia cost $43 a day, and a hospital bed is $430. I don't know; pick a number. And so we are also going to be looking and our research will pick this up as well, as to whether or not we actually increase our use of hospital bed days or decrease our use of hospital bed days.

We have to account in our system every time an older person goes into the hospital because those are days we do not earn money to purchase the services on their behalf. Our sense is—and I do not have the control group data—is that we have had an opportunity

to forestay hospitalizations because people get ongoing adequate care.

What is so common under the current medicare system, because you must be skilled-care qualified to get services in the community, is that an older person has an acute health problem, is hospitalized; that health problem is brought under control; they are discharged and get several weeks or maybe a couple of months of nursing care.

And as soon as they gain a plateau, the skilled services precipitously end because custodial care is not covered under medicare. We see a decline, then, and so there is this vicious cycle of acute health problem, in-home short-term skilled care, no care, precipitous decline, and back in.

We think that the long-term care breaks that cycle, that vicious cycle. Again, the data will tell.

Chairman HEINZ. And will tell us whether savings occur?

Mr. EISENBERG. We will know that from the research if that is true.

Chairman HEINZ. Are you picking up any data on the extent to which more people use services than otherwise would, because there are an awful lot of people out there who are somehow just getting by. It must be quite a struggle. I assume some of those people would be—well, Mr. Swain might have been able to get by without institutionalizing his mother. He might have quit his job or worked a very short time. If he tried to work, he might have wondered if he wanted to get up the next morning at 5 a.m. and go to bed every night at 12:30. It could have happened to him.

There are a lot of people who are being cared for in the home and yet need a higher level of care.

Mr. EISENBERG. Yes; I think there are a couple of options for people who genuinely need care. One is to get no care or to get inadequate levels of care, and that is certainly a decision that we could make in terms of public policy. Our experience with our clients—and this may come as a surprise, although I think not—is that families do not dump responsibility for caregiving onto the project.

We are real sensitive to that because we have to stay under budget. And we are trying to make a case that in-home, long-term care is economically viable. In fact, our experience is that families do very well, provide unbelievable amounts of in-home care, but then burn out. They just cannot sustain it. So while it is true we may be providing service to an older person who ordinarily would not get service, we are also sustaining families in their caregiving, and making it so that they can stay involved for a much longer period of time, forestaying institutionalization.

Chairman HEINZ. I am not surprised to hear that. I think what you are doing is extraordinarily valuable. From your testimony today, it sounds like you are off to an extremely good start. I guess all of us regret that it is going to take a couple more years to find out just how effective what you are doing can be. But it nonetheless represents a good deal of progress.

So I just want to thank all of you. Mr. Swain, without you he could not have a demonstration project.

David, without you, Richard would not have been able to come and testify either.

Do you believe, as Richard said, that the people who ought to be involved here should be people like the area agencies on aging when it comes to the brokering of care?

Mr. EISENBERG. I do.

Chairman HEINZ. We will just leave it right there. I do thank all of you for your excellent testimony. We appreciate it very much.

Mr. EISENBERG. Thank you, Senator.

[Brief recess.]

Chairman HEINZ. We are back in session.

If anybody was curious as to the flurry of whispered comments up here, we just got word that the Supreme Court has made a non-decision on the *Pennhurst* case. They have decided on a reargument, which I am told means that no decision will be made for another year. Not being a lawyer, I feel that I am constrained to make no further comments, but I know people in the audience were interested in knowing the outcome, so I wanted to let you know what happened.

First of all, we have righted the scales of justice here, after hearing from people from Harrisburg and Philadelphia. We now have two distinguished witnesses from Pittsburgh. I refer to Dee Rodrigues, who will be our first witness, and Karen Kelly, who will be our second witness.

Let me ask you, if I may, Mrs. Rodrigues, to please proceed.

STATEMENT OF DOLORES RODRIGUES, PITTSBURGH, PA.

Ms. RODRIGUES. I am Dee Rodrigues, and I am from Pittsburgh, Pa. I am the mother of three children. My oldest daughter, Renee, is mentally retarded and multiple impaired.

She was born 12 years ago, and she was apparently healthy, but within hours of her birth, Renee's heart stopped beating, and there was a lack of oxygen to the brain, which caused severe damage to the optic nerve. There were seizures that caused irreparable brain damage and cerebral palsy.

At 12, Renee is almost totally dependent on us for her care. She is not toilet trained, she cannot walk, she cannot feed herself, and she is unable to speak.

When I became pregnant with my third child, I prayed that it would be a boy, just so that I would have someone to help me lift Renee as she grew older. That would not have been necessary if there had been programs and services available to my family in the community.

Renee will never leave our home. She is our little girl, and I am responsible—my husband and I are responsible for her. But I really could use some simple services, like trained babysitting, and someone to sit with Renee while I take my other children to the doctor's, or so that I could go grocery shopping.

It is almost impossible for me to push a grocery cart and a wheelchair at the same time. You just cannot do it.

My husband and I are saving the State thousands of dollars by keeping her at home. And I understand it costs an average of $45,000 a year for a resident in a State institution. If we could just

get some inexpensive services, like respite care and trained babysitting, it would help so much because as of now, she is receiving nothing but her public school education, which is about 6 hours a day.

I know I am not alone in this situation, and many of the parents that I know who have chosen to keep their handicapped children at home with them are faced with the same problem.

Often, parents are frustrated and they are forced to seek residential placement, only to find that these placements are not available to them.

Someday Renee will be heavier. I will be older. My son is entitled to a life of his own. He may marry and have a family of his own. I worry about that day, and I wonder how my husband and I will be able to lift Renee in and out of the tub or into bed at night.

But I refuse to place her in an institution. But I really do not know how we will cope.

Then there are other worries that thousands of parents of mentally retarded children face. When Renee turns 21, her schooling will be ended. What then? I know that many parents who are faced with no day programing, no vocational services, no job placement for their children after graduating, it makes it so difficult for them to keep their child at home. I have 9 more years to worry about this.

My major consideration for all parents is what will happen to my child after I am gone. We have made arrangements for my sister, who is younger than I am, to care for Renee. And I also hope that Renee's brother and sister also will help with her care.

And I am lucky in the sense that I have someone who can pick up where I left off. But for many, many parents, that is not the case. And they look for alternative living arrangements only to find that there are long, long lines on these lists. Sometimes it is even impossible to get your name on a list. That is how difficult it is.

I hope that you, Senator Heinz, and other decisionmakers will have compassion and make the changes necessary to get the services that we desperately need.

The care of a severely handicapped child is frustrating. It is physically and emotionally draining at times. I just feel that if something is not done, the quality of life for our kids will diminish.

Parents desperately want to keep their children at home, but sometimes you just become so overwhelmed, and just afraid, that you need these community services so that you can keep your child at home.

Chairman HEINZ. Thank you very much for a very real example of a parent who obviously has a great deal of love for their child.

Let me ask Karen Kelly to be our next witness.

Ms. Kelly, as I understand it, has just become the president of the Pennsylvania Association for Retarded Citizens. I understand you have been active not just in Pennsylvania, but in several States.

Ms. KELLY. Yes.

Chairman HEINZ. Including Nebraska and New York.

I understand you have been a supervisor of the Early Intervention Association for the Association To Help Retarded Children in

New York, and you received a volunteer award. Congratulations for all your noteworthy efforts, and please proceed.

STATEMENT OF N. KAREN KELLY, PITTSBURGH, PA., PRESIDENT, ASSOCIATION FOR RETARDED CITIZENS OF PENNSYLVANIA

Ms. KELLY. As you mentioned, I am the president of the Association for Retarded Citizens of Pennsylvania. But most important, I am a mother of six children, and one of them is Jimmy, who is 13 years old.

He has cerebral palsy, epilepsy, he is blind, and severely retarded. And he is one of the 97 percent of retarded people who live in the community, in the Commonwealth, either living at home with their families or in small residential facilities. Last month, this whole issue of moving people from large facilities into the community came dramatically to my attention when I visited a facility of 132 adults in Allegheny County to investigate the report that a cattle prod was being used for programing.

The director said that report was true. When we left, we took the cattle prod with us. Supposedly, it was used as behavior management.

This is one of many instances where the association has been involved with abuse. Some I have personally witnessed. Months before that, I had been at another State center in the western part of the State in a so-called cottage. I walked into a room with 22 women severely, multiple handicapped, and no staff in sight.

The director of that facility who was with me was as embarrassed as I was shocked and concerned.

You have already mentioned the pregnancies at Ebensburg. We are also concerned about Pennhurst, where an undercover investigation discovered 15 residents who were being abused by over 20 staff people.

Just recently, Nicholas Romeo, who was the plaintiff in the U.S. Supreme Court, whose decision was that he should be free from abuse, was found recently to have been beaten very severely with a brush.

These and many other incidents deeply concern me as a person and as president of the Association for Retarded Citizens. And we have looked at—and I have personally studied—certain studies to see what is the best and most appropriate care, according to research.

So, this is not based just on personal opinion. There have been several significant studies done in just the last 2 years. I would like to briefly give you the results of those studies.

Touche Ross, a CPA firm, was hired by the State of Nebraska recently to look at comparative costs of institutions and community service. They were hired by the State of Nebraska to defend the costs of the institutions.

The results were that they found out just the opposite of what they expected. Not only was community care more appropriate, but it was less costly. In the entire institutionalized population of Nebraska, they could only find eight who could not be served by the present community services in Nebraska.

You are probably also familiar with the Temple University study, where 70 former Pennhurst residents now in the community were compared with 70 similar residents still in Pennhurst. Again, lower costs and more appropriate care were provided in the community.

The New York State Commission did a similar study of former Willowbrook residents. Again, the same results. Study after study is showing institutional care at higher costs and providing less appropriate programs. Let us now look at some actual cost comparisons.

Of the Federal dollars spent in the Commonwealth, $153 million, or 79 percent of the total, serves only the needs of 13 percent of the people; $31 million, or 16 percent of the total Federal dollars serves 1,800 people in the private, intermediate care facilities. But most shocking is the fact that $9 million, or 4.8 percent of the Federal funds serve 82 percent of the retarded population.

Now, this is the population presently served. We are not talking about the waiting lists or the unserved people in the community. And according to the Governor's——

Chairman HEINZ. This is strictly for the developmentally disabled?

Ms. KELLY. Strictly for retardation. And I am only talking numbers served, presently served.

The University of Minnesota did a study of how many Federal dollars could be saved if people—the same people now being served in institutions—were to be served in the community. The result of their analysis was that within a 5-year period, $3.5 billion would be saved and thousands of retarded people would be served more appropriately.

To bring it closer to home, I am sure you are familiar with the closing of Marcy, one of the institutions that was mentioned earlier.

However, they did not mention some other startling dollar savings and the fact that more people are now being served in a far more humane way. A total of $3 million was saved the year the facility was closed. Additionally, $1 million a year has been saved since the closing.

More significantly, over 160 people were placed in the community and their programs are carefully monitored. But more importantly, 85 retarded people living in the community who were on waiting lists are now also being served at $1 million a year savings to the taxpayers. Admittedly, we still have waiting lists. And as Dee mentioned, there is still a desperate need for services in the community.

In Allegheny County, we are proud of our community services. Per capita, we have the largest number of group homes in the Commonwealth: 555 retarded people live in CLA's—community living arrangements—at a cost of about $80 a day.

We also have 38 people living in host homes at a cost of $21 a day. You would probably add $20 to $30 more per day for their day programs. Day programing is provided by the school system for children.

So, the cost of the children to the State is $21 a day. Probably more important and something that Dee and I are concerned

about—my son lives at home—are the vast majority of retarded people who live at home with their families. We want to keep our children at home, but we need some services.

There was a study done at the University of Pittsburgh 2 years ago by a parent of a severely, multiple handicapped child. She did a study of what would it cost to keep a severe multiple handicapped child at home. What would be the actual cost if families had everything they needed? She took five families of different incomes, low to quite high, and she asked, "If you had everything you wanted to help you in the home, what would you need?"

I happened to be one of those families. I needed an elevator and babysitting. Other parents listed their particular needs, such as respite care, camping, transportation, and so forth. The average cost for each family was $7,100 to provide for all services needed to keep their child at home. That included use of a van with a lift, an elevator for some, child care workers, and so forth.

I will be glad to share this study with you.

An additional $10,000 would provide all necessary medical equipment for the five families. In other words, $45,000 a year would provide for all the needs of five severely handicapped children in their homes. That happens to be the identical cost to keep one person in a Pennsylvania State center for a year.

The waiver will be used next year in only a few counties in Pennsylvania, and that took a lot of energy for us to convince the Commonwealth to do. Instead of a few counties, the waiver should be used statewide. And we are very concerned that it will not be.

We are interested in the soon-to-be introduced community living amendments of 1983, where the Federal dollar would slowly, over a period of time, be funneled from institutional use to community services. I think the facts, figures, studies, and my own personal experience demonstrate clearly that community care is less costly, but more importantly, far better for retarded people. We think that it is time that 97 percent of us also get some help from the Federal Government, so we can keep our children in the community where they belong.

Chairman HEINZ. Mrs. Kelly, thank you very much for some very startling financial analysis, not only drawing from your personal analysis of families in what I gather are in similar circumstances to you, but also the budget of the Commonwealth. I am well aware of the Community Living Act of 1983, which you have mentioned.

It is a subject that I and others will be looking at much more closely. The testimony being presented here today is very helpful to me as a means of becoming better informed on all of the issues involved.

[The prepared statement of Mrs. Kelly follows:]

PREPARED STATEMENT OF N. KAREN KELLY

I am Karen Kelly, a resident of Allegheny County, the president of the Association for Retarded Citizens, Pennsylvania, and an officer of the Governor's Advisory Board on Mental Health/Mental Retardation. I am the mother of six children.

I am here to talk about the movement of retarded people from institutions to community services, but before I begin I want to make it clear that the vast majority, approximately 97 percent, of mentally retarded Pennsylvanians already live in the community independently, with their families, or in community residences.

Last month, the issue of moving people into smaller community homes or helping families keep their children at home became even more critical to me when I went into an Allegheny County facility housing 132 people with mental retardation to investigate the use of a cattle prod on residents.

The prod was used to keep three severely retarded persons from "abusing themselves." It carried a shock of eight volts and cautioned, "This instrument is to be used on animals only." Use of the prod has been approved by a consulting psychologist.

This is just one abuse incident. In the last 9 months, the ARC has been faced with a number of serious situations in large institutions. For instance:

In August, a 5-month undercover State Police investigation at Pennhurst Center revealed that 15 clients were victims of ill-treatment or neglect. One mental retardation aide was arrested for assault and harassment and 21 other employees were implicated in the case. Because of the *Pennhurst* court order, the Chester County institution is one of the best monitored institutions in the Nation, and yet abuse persists.

In December, the ARC found that two nonverbal, severely retarded Ebensburg Center women had been raped and impregnated. The State Police are investigating the case and are focusing on staff people as suspects.

On March 31, Pennhurst Center staff discovered bruises made by a hairbrush on Nicholas Romeo's back, buttocks, and chest. The State Police are investigating. Six years ago, Romeo's mother filed suit against Pennhurst seeking better protection of her son who had suffered 77 serious injuries during a 2-year period. The case went to the U.S. Supreme Court and resulted in a landmark decision involving institutional residents' rights. Despite the well-publicized court case and special individualized protection, Romeo was again beaten.

The Department of Justice and the FBI are currently investigating the possibility that beatings of Pennhurst Center residents during the past 5 years have violated their civil rights. The Federal criminal investigation is not tied to earlier State Police inquiries. A grand jury may hand down indictments in the case.

This continuous chain of abuse has led the ARC and many parents to believe that it is impossible to stop ill-treatment in institutions. The solution is small community living arrangements and programs that will encourage families to stay together.

A study conducted by Temple University of 70 matched persons who left Pennhurst with 70 who stayed showed that those who left received more services for less money and improved over those who stayed at the institution.

Community living arrangements (CLA's) have an average annual per person cost of $20,121 compared to the $45,000 annual average cost of keeping someone in an institution. We've proven CLA's are better and over the years we've also shown that severely disabled people can thrive in them. For instance, in 1981, only 21.97 percent of the 3,885 people living in Pennsylvania CLA's were severely/profoundly mentally retarded. One year later the number of people living in CLA's had increased to 4,096 and the percentage of severely/profoundly retarded persons residing in these homes had risen to 25.83 percent.

The Pennsylvania Department of Public Welfare concluded from these results that "Pennsylvania CLA's are serving an increasingly more difficult population."

While the quality of care and who is served is upmost, the economics of the mental retardation service system provide a broad picture of twisted priorities.

Pennsylvania's Governor Dick Thornburgh estimated in his 1983-84 budget that 55 percent of the available funds, $535,515,000, for this State's mental retardation program would be used to support approximately 6,500 institutionalized persons, or 13 percent of the retarded population being served in this State. Their annual per person cost under the Governor's budget would run an average of $45,000. Meanwhile, over 39,000 people using community services and living in private intermediate care facilities would compete for the remaining 45 percent of the available funds. These figures have led the Pennsylvania Department of Public Welfare to estimate that 10,000 mentally retarded people immediately in need of community services would go unserved through 1986. Simply restated—13 percent of the population served would use 55 percent of the money, while 87 percent competed for 45 percent of the funds.

I find it appalling that so much money has been restricted to institutions, but I realize why it has happened.

Medicaid, the largest source of Federal money for mental retardation services, has been almost totally restricted to institutional use. In order to access the Federal dollar, States have been forced to upgrade institutions and keep them filled to their allowable capacities. This isolation of Federal money, which must be matched by State dollars on an almost 50/50 basis, has caused an intolerable lack of community

service dollars. And, when I say community services, I'm not just talking residential care.

The Association for Retarded Citizens, U.S., is supporting draft legislation that would alter the flow of medicaid dollars. The bill has not been introduced in Congress but we are working on finding cosponsors to help pass "The Community Living Amendments of 1983."

If this draft survives the legislative process, it would mean a dramatic increase in community services. Over a 15-year period, medicaid would be shifted gradually from the institutions to the community. More small community living arrangements would open and families coping with retarded children at home would have available to them a full array of services presently stifled by a lack of funding. These include respite care, family support services, habilitative programs, recreation, counseling, attendant care to help lift, bathe and care for a disabled family member, physical and occupational therapy, early intervention, etc. These services would in the long run, save the State and Federal Government millions.

People from all over the United States are joining together to move this bill. They, too, have found that the distribution of Federal funds is unequitably weighted to institutional care. In Pennsylvania, the Governor projected that 79 percent of the Federal funds available next fiscal year would be used to serve only 13.9 percent of the population—those living in Pennsylvania institutions. Only 4.8 percent of the Federal moneys coming into this State would fund community services needed by 82 percent of the mentally retarded people receiving services.

I came here today not only as a representative of the Association for Retarded Citizens, but also as a parent of a multiple handicapped, nonambulatory, severely retarded son. Jimmy will never know the hardships of institutional life, but as he grows I fear that we will not be able to continue to care for him in our home without help. I see the "Community Living Amendments of 1983" as a solution to the problems we will face in the future as Jimmy's parents.

Just give me and other parents in the same predicament a small percentage of the $45,000 spent on each institutional resident and we will continue to keep our kids loved members of our households.

I know that I could meet Jimmy's needs on this small percentage. A study done 2 years ago of five families in Allegheny County caring for their severely retarded children at home, showed that these kids' daily needs, i.e., trained baby-sitting, respite care, attendant care, etc., could be met on an annual average of $7,100. With special equipment such as vans equipped with lifts and elevators in the home included, the cost came to only $9,100.

We need the "Community Living Amendments of 1983," Senator Heinz. I hope that you will be instrumental in helping us break down the Federal barrier to the medicaid funding of community services by supporting this legislation. If you do, you will be a hero to thousands of families of retarded Pennsylvanians who are now unserved.

Chairman HEINZ. Our third member of the panel is Polly Spare. Ms. Spare is the president of the Pennsylvania League of Concerned Families of Retarded Citizens, Inc. She has served on the Pennsylvania State Task Force on Right to Education, on the board of the Eastern State School and Hospital, and Pennhurst Center in Spring City, Pa. And I understand that you have also been somewhat active in the litigation of Pennhurst.

Ms. SPARE. Yes, sir, I have.

Chairman HEINZ. And further, that you have a bachelor of science in research and bacteriology from Tufts University.

Ms. SPARE. A bacteriologist and now an advocate for the mentally retarded.

Chairman HEINZ. There is no doubt about the latter at all.

Ms. SPARE. I am the senior citizen member of this panel. You look skeptical, but I am, sir.

Chairman HEINZ. It is a good thing I did look skeptical.

STATEMENT OF POLLY SPARE, DOYLESTOWN, PA., PRESIDENT, PENNSYLVANIA LEAGUE OF CONCERNED FAMILIES OF RETARDED CITIZENS, INC.

Ms. SPARE. That is right, I am very close to being a senior citizen. I have a retired husband. I have two severely, profoundly, multiple handicapped children. The greatest mental age achieved by either is 18 months. I am a parent. I have been a volunteer in all services and an advocate for the mentally retarded for 28 years. I would guess you would say I am a professional parent.

I am reality oriented. I have been through it. I have been through what Mrs. Rodrigues is going through now.

I serve people who need the same services, and I serve people who are far older than I. I think because I do I can bring a perspective, and because I am a Pennhurst parent, I can bring a perspective which you really have not heard from other members today.

First of all, our league is new. We are an affiliation of groups of people statewide. We are informally affiliated with other groups throughout the country. We have grave concern about the direction that is currently being proposed for people who require residential services. We know that because of our age, because of our family situations, because of the lack of caring, basically, among the general population for our problem, that we must find a solution and a way to protect these people before we die, to be quite blunt.

Many a parent has said they would rather see their child dead than to be at the mercy of a community that is dependent on the Federal dollar. I do not think we can place mentally retarded people in strictly community settings with an SSI check or social security check. It is insufficient for the majority of our senior citizens today to even basically live, and our people are totally helpless.

They are probably the most deserving of the handicapped people. They fit into the same category as some of the stories that went with some of our aging. I have that same situation in my family. I know the problem it is. I have a stepfather who is 83, brain damaged from surgery 6 months ago, who is still surviving. He has a gastric tube to feed him and no ability to do anything anymore.

He is sheer expense to our family. This is the greatest way for a family to be destroyed.

I wanted to talk to you a little bit more about the Pennhurst litigation. I want you to know how we see it, we as parents who have been through this. I am a former ARC president in Bucks County. As my testimony indicated, I have been involved to the extent that I started the sheltered workshop program for the ARC movement in Bucks many, many years ago.

Chairman HEINZ. Let me just say that your entire testimony will be placed in the record,[1] again in full. And I have a number of other examples of testimony that you have previously made, which will also be made a part of the record.[2]

Ms. SPARE. Thank you, sir.

How do we see this? We parents have come to see this as a power struggle, a struggle between the courts and the Commonwealth as

[1] See page 47.
[2] See appendix, item 1.

to who has the right to make a decision about what will happen to our people. We ought to have some voice in that, and we as parents have had just about no voice.

We have been through the agony of three levels of Federal courts, and as you indicated, we are going to go through it again. In the meantime, some of our people are being put out.

We have been oppressed for many years. We have no rights. We as parents of severely, profoundly, multiple handicapped children have no right to say that we do or do not approve of a placement. We have to take what we are given. We have taken all we want to just take. We feel that we are able to participate. We are able to give people like you and your committee input. We have done it here in Pennsylvania. We have been involved and I have been involved in helping to develop a new act or a proposed new act for mental retardation services here in Pennsylvania. We have just completed that work.

We feel that a great many self-styled advocates have determined that they can make decisions for us. We do not think that is necessary.

We tried very hard just a little over a year ago to get rights as parents by establishing and having introduced a bill that would have given us a natural guardianship. At the same time, a part of that piece of legislation would have limited input by the courts.

We lost. We, as parents, were willing to lose all of our rights to legal intervention for the opportunity to eliminate the courts in the decisionmaking process for the mentally retarded. We are seeing far too many attorneys determining what is best for our children. We are seeing some of the same attorneys being responsible for and making determinations of what is the best program for our children. They are attorneys, sir, not mental retardation professionals.

What this litigation has meant to us is that we are thinking in terms of the way people look at our children at Pennhurst, how they come in and look them over and decide which ones they want, which will fit into their situation. It is very similar to a situation we had in this country 150 years ago.

People looked over the slaves and determined which ones they wanted. Many of us have children that nobody wants, and if they do want them, they want them only for the money they generate.

Mental retardation has become one of the biggest businesses in this country. There is more money in our mentally retarded people than in almost any situation.

It has been difficult—and I have never verbalized this as loudly as I am doing it today, but this is the only opportunity we will have—we do not have an equal opportunity in this Commonwealth. I heard our deputy secretary quote figures to you about costs of care in our facilities. I was part of the original special master's office under Judge Broderick's orders. I was certified as an advocate. I am still doing advocacy. I am no longer part of any committee, anything to do with that. There is no special master, but I still serve as an advocate for families who come before the hearing master. I just placed someone who costs $185 a day, and I advocated for that $185 because without it, my client would not have had

any kind of assurance that that program, which had been designed for him, was going to be carried out.

I sat through 5 hours listening to the Commonwealth, the county, and the provider argue over who was going to provide him with a hearing test. There is more in my testimony with regard to this case. I am not going to go into it.

We cannot mandate that the citizen is going to love our handicapped child. We cannot mandate caring or loving in anybody, no matter how much we would like to. The American Psychiatric Association, Senator Heinz, has just changed its position on DE institutionalization. The American Psychiatric Association, when it met here in Pennsylvania, a matter of a couple of months ago, openly admitted that a great deal of what had been idealism has not proven to be fact.

I am old enough to have lived through a lot of this, and it does give me some opportunity to speak with wisdom. Philadelphia is full of street people. Pittsburgh must have its street people. New York City has its street people. We do not want our children to be street people. If and when the Federal Government and the State government no longer see fit to fund us, then we will have no options.

Many a parent has said that they would kill their child first before they would die and leave them this way. This may sound dramatic, but it is very real. I have seen this happen. I have also seen people left behind. Here are a few examples of parents and what they have been through in the Pennhurst litigation, I have some additional copies which you may have for your record and for the other Senators.

This little article [holding up one of the copies] represents what happened to one woman who was in one of our private licensed facilities, not currently involved with the Commonwealth of Pennsylvania. She happened to be a Pennhurst class member. She had been in a private facility, which served 37 people for over 17 years. Her county came along—at the direction of the office of mental retardation to reduce the population in the private licensed facilities, and said she is going into the community.

They tried to put her in this program, Senator Heinz. You probably recognize the cover [holding up copy of report]. It is an audit by our Auditor General's Office here in Pennsylvania. The provider that they tried to place her with had been demonstrably shown to have made $400,000 profit in 1 year on private placements in his facilities.

The girl had been originally placed, the woman, I should say, because she had been repeatedly raped in the community and beaten. She could not even get to and from a program without being picked up. She would disappear for days. Her family placed her. That woman, as a class member, was entitled to service from the hearing master, and I tried to get that service for her. I was unable to because the Commonwealth transferred her not to the community because of our objection, but to another private licensed facility, cutting off our access to the court.

Where they transferred her to was a larger institution at twice the cost. So, I find it very hard to contain myself when I hear discussion about looking for the most cost effective alternatives. The

Pennsylvania league is asking and will continue to ask that we look, really look at the broad range of alternatives, not just little facilities for 8 or less or 16, but for some mentally retarded people the only way is to provide them a larger facility where we can afford the professionalism that would give them services.

Now, I am not saying that has to be an institution for 5,000 people, but I am saying that that facility should be equitably entitled to the same quality and availability of services as we have for the community.

Our institutions are not. If we have abuses in the institutions, we have them in the community. I will not bore you with the details.

Why do we object? Why does the Pennsylvania league object? Why have people around the country flooded your Washington office with requests for you to not give support to this bill? There are probably as many of us who do not want it as who do. We are not ready, Senator Heinz. We have no guarantee and no proof that that system out there in the community is ready to receive our children.

Not only is it constrained by funding from the State and Federal governments, but we do not have the providers. We do not have the quantity, the quality, the experience that we need. We have some good ones. We have some excellent programs in the community, and some people should be in them. But for those people who cannot fit into that structure, we need something else.

And they should be as entitled to a staff ratio, which is 3 to 1, if that is what they need as community residents. That is not existent today.

You were correct, sir, when you said that the per diems increased appreciably as the population decreases. That is true. It is natural. It is commonsense. We fear that the Federal Government has not got an endless pocketbook. We know that. We are taxpayers. We feel that the authors of this bill who are responsible for the Pennhurst litigation are parents who acted against other parents.

I have sent you testimony and information on that subject. We were given no warning. And not only is Pennhurst the only one involved, but there is a whole group of people out there called the class. They are living in some very fine private licensed facilities, as was this lady.

They are most cost effectively cared for in that environment. We should not remove them. All we need in this structure is the opportunity to accept the fact that some people will not grow. I wish I could make my children grow. I would have given them anything. We gave up everything in our earlier life to provide them with private schooling, the best of specialists.

I have been privileged to have the opportunity at an early age to do this. I could not afford to do it on an ongoing basis with the two children, but I do think my two children who are in an institutional setting, are as entitled to consideration as any other child.

Why do we object? We do not see that the money that would be released by releasing our children could be stretched any further to provide for other people. I sent you copies of a series of pictures depicting a Philadelphia CLA. That is not unusual. That client who was to go into that CLA will be far better served in an institutional

structure. He is very destructive, hyperactive. His parents do not even live in the State of Pennsylvania.

I have had Philadelphia parents who are caught in the 2176 waiver call me and say "they cannot send my child to county." They are sending them out of the counties and the providers are taking them. If the provider has a spot and a county has an available funded placement, they are placed. So Philadelphians are going to Lancaster, to Montgomery, to Bucks. I do not know where our children are going to be. This was all designed to provide us with a better opportunity to have care closer to home.

The care closer to home that I need is available in my backyard. I cannot accept it. I am not allowed to because it is called an institution. It is a large and internationally known licensed private facility. It would provide my son and my daughter with the kind of care that they need and the kind of care that many other people who are severely retarded people also need.

Monitoring. It is not nearly as glamorous as the description that was given to you. We can tell you. We know. We, the parents of the Pennsylvania league, were asked by Judge Broderick to prepare for him a possible monitoring and advocacy structure that he might consider. We did it in the timeframe that he asked, not professionally done, but done with our experience and with our knowledge and with our ability to recruit people like ourselves who really care to be involved, the most cost effective, least expensive alternative in this State that I have seen. What happened? The Commonwealth, plaintiffs, and defendants got together, so by the time we got back to present it to Judge Broderick, nobody would accept it.

Parents are not informed; parents are not communicated with. We are to be kept on the outside. We are expected to deliver our children into the hands of people who are looking for this, who already are representatives of groups or chapters throughout this State who are very heavily funded as a result of deinstitutionalization.

I could say a great deal more. I believe I have said enough. I am open to questions.

[The prepared statement of Mrs. Spare follows:]

PREPARED STATEMENT OF POLLY SPARE

Gentlemen: I will present today on my behalf and for many other families whom I represent as advocate and friend.

I am a parent of two severely profoundly mentally retarded individuals now 27 and 30 years of age, with mental ages of 9 to 16 months and 18 months respectively. Both currently reside in Pennsylvania State facilities. Both in their earlier years had the opportunity to attend private facilities.

My background in MR began locally with Bucks ARC 27 years ago, and I served as one of the original certified advocates in the office of the first special master. I was also involved in the State planning process for MH-MR prior to the passage of our 1966 act. I convened the first MH-MR advisory board in Bucks County in January 1967, and served as chairman for 5 years.

I am currently a member of that board, having just been reappointed in January 1982, for a 3-year term. PPSA, Inc., is an intervenor in the *Halderman* v. *Pennhurst* case, and Pennsylvania League of Concerned Families of Retarded Citizens, Inc., is a new Pennsylvania nonprofit corporation providing education, information, and advocacy services to MR people and their families representing the community, CLA, PLF, and institutions. In my presentation I shall make reference to some other involvements as they are relevant to specific situations.

When the Pennsylvania MH-MR act of 1966 was passed, it was then perceived to be what all MR persons and their families needed. Attached to my written testimony is a copy of a letter [1] written by me at that time to our then commissioner of mental retardation, Dr. Donald Jolly, stating that although I found the new ideal community living prospect exciting yet frightening, I was concerned about "overmandating and underfunding." It would certainly appear that we are here now because in these past 15 years we have indeed been overmandated and never has the MH-MR community system been funded at levels of request. "More" never seemed to be enough, and I am concerned that you will not be able to continue to escalate funding as you have over these past years. Personally, I don't think you should—not under the present discriminatory system of service delivery.

Coupled with a shortage of funding, I see a trend to move away from some of the excitement of the new theories of the past few years—deinstitutionalization, normalization, etc. Some professionals are even asking if CLA's and ICF/MR's are the way to go in the future. It would certainly appear from Governor Thornburgh's budget projections after 1982-83 that Pennsylvania is once again rethinking what we are doing. I'd like to see us extend (programatically, not fiscally) to a full range of available alternatives. It is possible.

I have not asked our Pennsylvania legislature for any funding since my experience in the early 1970's when, as vice chairman of the Southeastern Regional Welfare Advisory Committee, I was assigned to seek a $6 million supplemental allocation to open a then-completed but empty Woodhaven Center in Philadelphia. A series of meetings with House Appropriation Committee members, DPW officials, and the secretary of the budget resulted in—no need for supplemental funding. Startup costs had been allocated by the legislature but misappropriated by the department. Funding appeared—Woodhaven opened. My analysis of Governor Thornburgh's budget for 1982-83 (available from me on request) raised questions about the full availability of a specific institutional budget—Pennhurst Center. I ask in this report how valid any facility budget can be if there is an impropriety with any one.

We are currently spending millions of dollars on highly specialized programs requiring levels of professionalism not even contemplated when we first developed background information for the MH-MR act. In spite of all that we have done, all that we have spent, we have not met our stated commitment to MR people. Some few have excellent programs, some have programs of lesser quality—many still have nothing. The fiscal climate would indicate that we will see more people in this last category as time goes on. "Desperate" is a word often used by the caring case worker who is frustrated in his attempt to locate a service, never mind fund it. We are not providing at the level of need. One has to ask why?

My observations include the following:

(1) Some programs are just too expensive for the results produced.

(2) Severely profoundly mentally retarded adults should not be placed in CLA's, if they require 2 to 1 and 3 to 1 staff ratios.

(3) Sheltered workshops were not designed to serve severely profoundly nonproductive mentally retarded people (yet the Pennhurst court order requires a day program component).

(4) Workshops, per se, will have to be redesigned to mean "a work producing facility" manned by higher functioning people who can contribute in what should be an independent business venture not requiring substantial DPW financial support. (We have a start toward that in this county.)

(5) Illegal aliens should not be given priority for available publicly funded services when taxpaying citizens cannot avail themselves of an equal opportunity.

Just a few statistics for Bucks County:

(1) We have 150 persons waiting for day programing services with no money and no slots. At $40 per day (one of the established rates), we need $1,560,000 just for the identified current need in that category alone. That figure, of course, excludes anybody currently in programing and all those persons who will need it in the future. Currently, we do have an illegal alien who has (with legal intervention and county cooperation) been given what many legal residents cannot have. I have been working as chairperson of I.U. No. 22 with some of our families in need to develop community alternatives—some nonsalaried work placements will be available. Parents say to volunteer is preferable to day after day of TV, resulting in regression due to no programing.

(2) Someday many of these 150 "day" service types will need some kind of residential or supervised placement also.

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[1] Retained in committee files.

(3) We have 451 persons requiring some kind of service that is not available to them according to the MH-MR administration office.

I'd like to point out that I have seen dozens of plans and proposals developed at State and local levels over the years. All took tremendous amounts of staff time and money to produce. None have ever been fully implemented or ever will be. Yet, we produce more annually. I have seen our commitment to need and desire to provide become locked into a very restricted perspective by the Commonwealth of what MR people need. Simply stated, parents of severely profoundly retarded people know that their family members need good physical "hands-on" care, love and acceptance, someone to see that their basic needs are met (they are clean, fed and shown affection) and that they have "activity." We need to know that when we are no longer here there is someone to care for them. This care can be in an institution or a PLF or other group settings but always with assured supervision and staff. We cannot accept "independent living" on a social security check. We see this as the first step toward MR street people.

I'd like to know how parents feel about the Pennhurst litigation. It has left us isolated, without a democratic due process. It has meant denial of our rights as parents to meaningfully participate with our children. The Commonwealth uses court orders to "hide behind" with "we have no choice, your son or daughter must go into the community, there is a court order." OMR has developed a State plan to phase down and eliminate some institutional placements. (Example—C. H. Marcy closure in June 1982 and conversion of Cresson Center to 500 prison cells.) The criminal has a higher priority for quality residential care than the MR in Pennsylvania. Since the beginning of the Pennhurst litigation it has been obvious that the Commonwealth (defendant) and PARC (plaintiff) desired the same end result. Our offer to testify for the Commonwealth during the trial was rejected and we eventually realized that we must somehow intervene for our perspectives to be heard. The Commonwealth also objected to that action and we were again rejected by the district court. We were finally accepted by the third circuit court of appeals, allowing us the option to go to the U.S. Supreme Court. The Governor's office had to be coerced into appealing to that level. We have continually felt rejection by people who have responsibilities to provide for our family members. DPW has not even come out in support of the Morehouse family whose 13-year-old son has been removed from Pennhurst by court order in spite of their objections. They are not here today because they continue to pursue their constitutional rights in the third circuit court.

For years, we have attempted to initiate ongoing communication with DPW to no avail. Only PARC parents have been involved in planning and review processes. Only PARC people have been appointed to State boards and authorities. They do not speak for us. Before we returned to the third circuit court of appeals on remand from the U.S. Supreme Court late in 1981 we parents, through PPSA and Pennsylvania League of Concerned Families, Inc., lobbied in the Senate for passage of House bill 1824. It was a very restrictive measure, but we were willing to allow that you modify the act to eliminate "least restrictive" and our opportunity to litigate in the future, in exchange for a bill that would most assuredly have stopped the courts. PARC lobbied against House bill 1824, apparently with administration support. We lost and MR people lost. They will be denied even more opportunity for additional programing because attorneys must be paid. Plaintiff attorneys are paid with our tax dollars—our attorneys are not. We parents are most grateful for the generosity of AFSCME in helping to support us as we pursue the challenge of establishing an honest and fair system with the broadest possible service provision for all MR people.

Gentlemen, we request that you do away with "least restrictive," give parents the natural right to make decisions on behalf of their incompetent children and see that we have options. Courts, masters, and the Commonwealth have separated parents from their children. Plaintiff attorneys were appointed by the hearing master at Commonwealth expense to represent severely profoundly mentally retarded clients, placing their families in the defensive position of having to prove they, the families, were right. That was a no-win situation. As you look at revision, place the burden of proof on OMR and DPW. House bill 1824 or something similar could help to end this litigation. It is no longer a question of what is best for MR people, but who is more powerful—the Commonwealth or the courts. This litigation has pitted parent against parent, parent against child, has polarized advocacy groups so completely that we have now developed a distrust for anyone who is in authority at the State level because of their relationships with the plaintiffs.

I would like to devote my remaining time to my own personal problems. As I mentioned initially, I have a 27-year-old son and a 30-year-old daughter. In October of 1981, my son (Chris) was accepted at the Woods Schools, here in Bucks County.

Chris is a severely debilitated medically fragile young man with a mental age of 9 to 16 months. Because of lack of Commonwealth and county commitment to Chris, he was denied the opportunity to be transferred to Woods. There he would have been in a far more acceptable physical and programmatic situation at one-third the cost of his present placement. He would have had a 3 to 1 staff ratio for as long as he needed it, and the availability of a full array of supports. He would have been closer to his home, which is far more in keeping with the intent of our existing MH-MR Act.

Chris was denied the Woods Schools because it is not "least restrictive." This would have been the most appropriate placement for Chris, and still is. I also believe he was denied because of a personality conflict with Dr. Howse, resulting from my advocacy activity on behalf of parents throughout the State. In Altoona, in November of 1981, at a meeting called by one of your fellow Senators, Dr. Howse was asked to explain how she planned to disperse the 150 Cresson residents to alternative facilities. She offered the possibility of transfer to PLF's as an alternative. Less than 1 week before that, Chris had been denied that option by Dr. Howse and my county administrator. As invited advocate for the Cresson families, I asked her to be more honest with these people who were in an understandable panic, mentioning her denial of that service to my son. She responded by announcing to an audience of about 300 persons that I was the parent of two mentally retarded adults and had been troubled for many years. She said I sought for Chris what was needed for another person (nobody was awaiting placement—I checked) and that Chris was part of the Pennhurst class (he is not).

I have recently been told that now, 5 months later, Dr. Howse is still using legal counsel in an attempt to have him placed into the class. Why should she want to add anybody to the Pennhurst class when there has been constant legal action attempting to reduce the court mandate? We can't handle the numbers we have now. Her attempt to discredit me failed, but it does illustrate that as parents we suffer indignities from our bureaucratic professionals. They have lied to accommodate their needs and they have not communicated honestly. They accused us of being guilty because of our MR children and they expect us to accept their game-play with our vulnerable family members. Adversity has made us strong. We parents who have survived the tragedy of a birth of a defective child have learned to face reality. We see our children as they are, not what somebody else says they can be. We rejoice if they achieve—we accept it if they do not. Within their MR grouping, they can vary as much as we so-called normal people do.

I want to tell you about my daughter Sandra, who has resided at Pennhurst Center for 16 years. On March 26, we received a letter from our case manager telling us that Sandra had been referred for "an appropriate and available placement" in an ICF/MR. A copy of that letter and our reply are attached to my written submission.[1] We have had NO response from anyone. Parents are ignored.

Sandra has a mental age of 18 months, is severely physically involved (complete thorasolumbar scoliosis), responds to some direction, but cannot dress herself or speak. She is defintely not a candidate for community living. She can contribute nothing to our society. The third circuit court of appeals recently upheld its prior opinion—"for some people Pennhurst Center would not be appropriate." She fits into that category.

At Pennhurst, she has a foster grandparent whom she adores, and staff continuity. She is not pressured into a social structure that she cannot physically or mentally cope with.

Like all other parents, I too will be told about the existing court order. Recently, OMR struck a consent agreement with the office of the special master. Our attorney was not invited to be part of this negotiation, so we have had no input. Now we have another layer of pressure. The Pennhurst implementation team (PIT), funded from the Pennhurst budget with eight staff positions from our administrative staff complement, will assume special master duties. We parents see only an additional layer of bureaucracy with which to cope.—PIT, the master who will continue to be there, the hearing master, and Judge Broderick who has consistently denied all of our submissions.

I would like to return briefly to Sandra's proposed placement and point out that the cost of this location would be adequate to fund Sandra, Chris, and one other resident at the Woods Schools, giving all of them the level of professional commitment they would need. Woods Schools recently offered to set up a Bucks County unit for our residents remaining at Pennhurst. OMR declined the offer. I find it unconscionable that OMR, because of a theory, should continue to pursue the devel-

[1] Retained in committee files.

opment of services that are excessively expensive and are dependent on an ongoing commitment from you as well as the taxpayer, who surely will revolt when he finds that nonproductive citizens are funded annually far in excess of anything he could ever hope to earn.

The whole system must come to grips with reality. I believe that my children are being used to harrass me because of my supportive involvement with people in need, and my willingness to speak out as I have today.

I thank you for your time and attention.

Chairman HEINZ. Thank you very much, Mrs. Spare. One question I wanted to ask you about is related to the section 2176 waiver authority. The law requires that there be necessary safeguards to protect the health and welfare of the individuals provided services through the waiver. Do you agree?

Ms. SPARE. Yes.

Chairman HEINZ. One of the things you are saying, of course, in your testimony very forcefully, is that the welfare and the health of the individual is not always being safeguarded.

And it is that to which you object.

Ms. SPARE. It is one of the concerns.

Chairman HEINZ. Now, my question is: Where is the fault? Is the fault with those who provide the services? Is the fault with the Secretary of Health and Human Services for having written inadequate regulations in the case of the mentally retarded?

Is the fault with us in having written this law? Where did we not make our law explicit enough? Where are we going wrong?

Ms. SPARE. I do not think we are all going wrong. First of all, the U.S. Supreme Court made it clear what they thought was the Congress intent. We should not have had to go back. I think your intent is good. I think the intent of the Mental Health-Mental Retardation Act of 1966 here in Pennsylvania was excellent. I helped to put it together. It was overmandated and overfunded from the beginning. I do not think we have the resources to develop ideal situations. For some people who can benefit, we should provide the resources. For those people who will require care all of their life, we need another resource.

I do not think that there has been any intent on the part of Congress or the Pennsylvania Legislature to do anything to impede the progress. Where we have gone wrong is the stacks and stacks of regulations that have become the law of the land. Our Mental Health-Mental Retardation Act of 1966 did not call for deinstitutionalization, least restrictive, or normalization, or any of the other terms which in many States have become buzz words.

I had not mentioned the eighth exhibit I brought to you today. It arrived yesterday from California. It is from the California Association for Retarded Citizens, supporting what I have been trying to tell you this morning, Senator Heinz.

I also have material from the State of Virginia. There are other States throughout this country who are ARC, who are not in support of the same position that you are hearing here today. That was to be my message. I was, hopefully, to be the first person that you would hear, since this is the first opportunity for us to be heard.

You will hear from other States, from other parents, from other groups. We are not all ARC. We should not have splinter groups. We should be able to work together.

Chairman HEINZ. As I have been listening to both you and Karen Kelly, I can see some differences of approach. I also see more similarities than I see differences, quite honestly. What I hear from Dee Rodrigues and Mrs. Kelly is that they want to take care of their own children as long as they possibly can.

Mrs. Rodrigues says she is worried about what is going to happen to her child if she is gone. And really you have echoed that comment.

Ms. SPARE. We have done it. We have been there.

Chairman HEINZ. You are worrying even more.

Ms. SPARE. Because I am a little bit closer, quite a bit older.

Chairman HEINZ. You are concerned about the issue of what control older parents have. You want to keep control. Other parents feel maybe they are unwillingly losing control because they are going to get too old and pass away. How will they fulfill their responsibilities as parents before they pass away? I am not sure, although there is a difference from the direction that people are looking at the issue; I think you are all seeing the same concern.

Ms. SPARE. Right.

Chairman HEINZ. One thing I am a little confused on is that you have, Mrs. Spare, a lot of reservations about the Community Living Amendments Act.

Ms. SPARE. Yes, I do.

Chairman HEINZ. And I gather it is your fear that it would be taken as a mandate for wholesale deinstitutionalization. Is that your basic concern?

Ms. SPARE. Partially, sir, for the reason that you articulated earlier, that as we reduce the population in the institution, we increase the per diem. That is the natural step that precedes, well, if it is that expensive, we do not need it.

We have seen it. I have been involved in trying to help parents from your part of the State.

Chairman HEINZ. So it would not be a matter of law, but a matter of incentives.

Ms. SPARE. That is right. It would be the alternative to the courts to gain acceptance for and support for an entire community structure.

Chairman HEINZ. And your second concern, as I understand it, would be that there is not sufficient services of the right kind now available in the community.

Ms. SPARE. That is right.

Chairman HEINZ. And I suppose a third concern of yours would be that there is insufficient quality assurance mechanisms to monitor the delivery of that care. And that would sum up your problem with community living arrangements?

Ms. SPARE. Partially. And the State's commitments, Senator Heinz. I sent you an analysis of the budget. The commitment to the community is only to the residential sector. The support services that they need to go with that commitment have been very deficient; they have been for years.

Chairman HEINZ. That was my second point: There are not the services available.

Ms. SPARE. The word has been if we do not get community services now, residential, if we do not get the CLA's, we never will. And

I think that I feel that this is the wrong way to go. You do not put something in place——

Chairman HEINZ. I understand. Hold it right there. I wanted Mrs. Kelly to respond to your concerns about CLA's because she is an advocate of CLA's. It seems to me that those are perfectly understandable concerns Mrs. Spare has made. How would you respond to them?

Ms. KELLY. I have the same concerns about any service that serves the retarded. My concerns are adequate regulations. And I do not think the ICF/MR regulations are appropriate. They are too medically based and they do not deal with appropriate programing. I think they should be changed. We have heard that they are going to be changed. To demonstrate the need for a change in regulations, let me illustrate from a recent experience. A facility, again in Allegheny County, a ICF/MR private facility, was audited 12 months ago by medicaid and the department of public welfare. It took us 12 months to receive that audit. That facility has absolutely inadequate programing. It happened to be the one that had the cattle prod. That will give you an idea of what it is like there. And yet they passed the audit, and they passed the licensing procedure from the department of health.

Something is wrong, and this is not a State center. It is a private ICF/MR.

I am concerned also that CLA's are properly licensed. We just started this year licensing CLA's—we, being the Commonwealth of Pennsylvania. I think that has been a jump forward, and I do commend the department for doing that, but that is not enough.

We, in Allegheny County, and we, as the Association of Retarded Citizens, monitor. We monitor not only the large centers, but we monitor all 19 providers who provide community living arrangements in my county.

We come in with teams of parents and we look at not only lists of requirements, but we ask ourselves, "Is this where I would want my child to live now or in the future?"

Chairman HEINZ. And these are licensed facilities?

Ms. KELLY. Yes; these are licensed facilities.

Chairman HEINZ. Why do you have to do that? I am going to be accused of a setup question if I am not careful. But why do you do that if they are licensed facilities?

Ms. KELLY. Because licensing is not enough. And I agree with Polly. We do agree on lots of things. I think parents have to be out there looking and making sure that all services are provided: safety, appropriate programs, and so on.

I wish we did not have to, but I think it is essential for an outside independent group to monitor quality care.

We are providers, by the way, so we ask another advocate agency with no connection to us to come to us unannounced and come look at our group homes. We may not be so great, either.

Chairman HEINZ. The previous panel had to do with the elderly, not with the mentally retarded. Nobody on that panel suggested that there needed to be a posse of senior citizens checking up on the area agencies on aging, as you are. Let me ask the question before you answer it.

There clearly appears to be a significant difference. Why is it? What is the nature of the difference that you need a posse of parents here, where you do not need a posse of senior citizens?

Ms. KELLY. I would disagree. I am very interested in the elderly, and I do think programs for the aging do need independent evaluating monitors. Abuses occur with the elderly also.

Chairman HEINZ. So you would say it is necessary in both cases?

Ms. KELLY. Yes.

Ms. SPARE. May I address the question of monitoring?

Chairman HEINZ. By all means.

Ms. SPARE. Just about 3 or 4 days ago, I talked to a person in California who is very much involved with the California ARC. Their director, who has been one of the greatest advocates for the full range of alternatives in California, indicated that the greatest failure of the community is the lack of monitoring. There was no way that they could afford to keep track of all of the small, scattered facilities that run the thousand miles from top to bottom in that State.

The same thing is true here, too. In monitoring, she is right; we do have to look, not because providers are bad——

Chairman HEINZ. I might short circuit this argument by simply agreeing with you, and I will give you the reason I agree with you. You may have caught it on one of the news shows, but it came to our attention that there was a nursing home in Texas City, Tex., which apparently passed all of its State examinations when it came to being certified and being inspected. Even so, other authorities found what they believed were grounds to indict the home for murder for failure to provide needed services. Murder by omission is what they called it. And it was given the seal of approval by the Texas health authorities. And it clearly was a terrible place.

Even so, we have had nursing homes with us for a very long time. They have been put under the microscope and the magnifying glass of Congress, aging committees, and the chairman of aging committees for the last 15 years.

Ms. KELLY. What we have discovered through our small facilities is, it is not just the monitoring teams who monitor—it is the mailman, the milkman, the neighbors who are doing their own kind of monitoring. And that is the real advantage of having the small home in the community.

It is amazing when things do not go right, sometimes we hear about it from the community. It is a good way of monitoring. Also the neighbors become involved.

Chairman HEINZ. Probably one of the toughest questions to address—I gather it is so touchy the Supreme Court could not answer it—is the question of parental consent, parental involvement. I am not going to try and address that issue here today. I think I will go read the nonopinion of the court before I try to.

But I would ask you this: When Secretary Cohen was here, he indicated what the State of Pennsylvania is trying to do is establish a process that does involve the parents and that does give the parent, I gather, significant input and implicit control.

Let me ask, since Polly Spare is probably the principal proponent of parental consent, are we making some progress in the Commonwealth in that regard?

Ms. SPARE. Senator Heinz, if we could have the support of the Association for Retarded Citizens to help implement the proposed new Mental Retardation Act, we will be giving parents a kind of responsibility and opportunity that they have not had. I know because I helped to draft it. And a review panel that is suggested in that law was suggested by myself as a result of conversations with judges from Allegheny County, who asked us to please get them out of our system--let us make the decisions.

Chairman HEINZ. Mrs. Kelly, are you in agreement with that?

Ms. KELLY. I will speak for myself. I just read the bill this weekend. I am not speaking as the Association for Retarded Citizens. We have not had time to really study the draft, but as Karen Kelly, a mother of a multiple handicapped child, I felt comfortable with the parent process in the bill.

Chairman HEINZ. Let me ask Mrs. Rodrigues: Is there anything—you are a parent and so are Mrs. Spare and Mrs. Kelly. Is there anything we have omitted in our discussions here?

Ms. RODRIGUES. Yes. I would not even be here today if we had the community services that we need. My husband has had to come home and turn down work opportunities so that we can go places, shopping, and whatever, run to meets for the other children.

So I just want to say that I am not here to institute workshops. I am not involved in any kind of advocacy. I am just here to represent parents who really care about their children and want to keep them at home.

Chairman HEINZ. Thank you very much. I want to thank all three of you for coming long distances. We appreciate your testimony. It is very valuable to us. Indeed, I say that not just to the three of you, but for all the other people who have helped make this a success. Thank you all very much. The hearing is adjourned.

[Whereupon, at 12:39 p.m., the hearing was adjourned.]

APPENDIX

MATERIAL RELATED TO HEARING

ITEM 1. ADDITIONAL STATEMENT OF POLLY SPARE, PRESIDENT, PENNSYLVANIA LEAGUE OF CONCERNED FAMILIES OF RETARDED CITIZENS, INC.

Senator Heinz, members of the committee, the Pennsylvania League of Concerned Families of Retarded Citizens, Inc., thanks you for this opportunity to share our perspective and give input to discussions surrounding the controversial issue of a national mandate for closure of institutional settings as a service alternative to mentally retarded citizens. In the 20 months since our incorporation as a nonprofit organization, we have become recognized as a long overdue resource for information, easily accessible and easily understood by the average family. Parents sought a resource not identified with support for just "normalization," "deinstitutionalization," "the least restrictive alternative," and a new vocabulary which defied definition. Advocates of this "new" philosophy had historically shown little or no interest in institutionalized persons or their needs and offered little support for the families who used these services. We had been referred to as "bad parents." Contributions from advocacy organizations to State centers were minimal, usually only at Christmas.

The ramifications of the Pennhurst litigation, my firsthand knowledge as a parent involved in that issue, and my visibility in the early ARC movement identified me as a person who could relate to their anxieties.

WHO AM I

I am a college graduate with postgraduate credits, but more importantly, a parent of two severely profoundly mentally retarded adults and two very normal adopted young adults. I have served on two State facility boards of trustees and was an appointee of the Pennsylvania Department of Education to the State Task Force on Rights to Education. I served as president of Bucks County ARC, developed the first sheltered workshops in my county and some of our earliest preschool programs. I worked on the task force which drafted our Pennsylvania MH/MR act of 1966 and I have just completed several months as a member of discussion groups in the Pennsylvania Senate giving input on legislative changes to produce the proposed "MR Procedures Act of 1983."

I live in Doylestown, Pa. I have been married 33 years to a recently retired senior vice president and actuary of a large life insurance company. I am a certified advocate, trained in the office of the first special master appointed according to Federal court directive in the Pennhurst case.

WHO AND WHAT IS PENNSYLVANIA LEAGUE

The League, as we have come to be known, is a totally voluntary nonprofit, private organization, incorporated in Pennsylvania, September 10, 1981. We provide individual and group advocacy services and all types of information.

Our board is composed of volunteers from professional and nonprofessional disciplines: law, public relations, accounting, business, and just plain parents. All are relatives of mentally retarded persons who live in State facilities, private licensed facilities, or in the community. We provide no residential or day services. We receive no public moneys. We are a grassroots volunteer human service effort, the development of which President Reagan had encouraged soon after his inauguration.

We are accused by our adversaries of being institutional advocates, but are, in reality, equally comfortable evaluating the appropriateness of a proposed community setting. I personally have done both. We are most accurately acknowledged as sup-

porters of a range of residential and programmatic alternatives from the community to the institutional setting, including the utilization of experienced private licensed facilities and the newer small ICF/MR which has now been implemented to its maximum objective and according to OMR personnel, will not be expanded because of demonstratively higher costs.

Appropriateness with parental concurrance is always our prime objective in placement. Equally important, should be a fair system to access the best service offered. Unfortunately, in Pennsylvania our institutions are administratively staff heavy, therefore costly, and not considered programmatically equal with small private provider arrangements. An example would be the far better staff-client ratios that exist in the community living arrangement (CLA). One to one is not ordinarily available in the institution (just about never) unless by special court order.

The Pennhurst Litigation

This has, without a doubt, been the prime catalyst in the polarization of Pennsylvania parents of mentally retarded persons. Our Pennhurst families were slow to react to indications that we were about to be "used" by persons calling themselves advocates of mentally retarded people in an attempted precedent-setting court case for closure of institutions.

We were not advised that PARC intended to intervene in a lawsuit filed by one of our parents to upgrade conditions at Pennhurst Center. Neither was the parent, original plaintiff Winifred Halderman, who later dismissed her attorneys.

PARC used a television exposé of "conditions" at the center as a basis for their secretive plan of action. At no time did they advocate with parents to upgrade conditions. Only recently, they admitted that even their membership had not been told of their planned action before they chose to entrap mentally retarded clients and their families (including persons not residing at Pennhurst), in an ongoing class action lawsuit now over eight years in process.

Pennhurst Parents-Staff Association, Inc., overnight, became a driving force toward seeking resolution of the litigation by the U.S. Supreme Court. We are currently awaiting a second decision on our February 1983 hearing. Some of our Pennsylvania legislators intervened with our Governor to seek his support for that relief.

Today, commitment to closure of Pennhurst Center by OMR appears to be proceeding at an accelerated pace. Between 1981 and 1984, we will have seen a 49 percent decrease in State committed funding to our facility. This year, we will be cut by $7 million, and in 1984–85, we are ordered to cut $13 million more and 450 staff positions. This represents a loss of close to 45 percent of our present 983 staff. Loss of matching Federal funds is greater than the Pennsylvania cuts. Exhibit 3, "Thornburg Budget Analysis 83–84, page 1."

ICR/MR moneys will follow our clients into community settings that offer an uncertain future under the 2176 waiver. These available tax dollars are encouraging development of private enterprise, with our people the pawns in a new system that makes promises, setting often unrealistic goals at a very high cost. Nobody will address the question, "What if Federal funding is cut?" Providers have protection in their contracts. Our people can be rejected from placement in a community living arrangement, be graduated to independence on a social security or SSI check, or be returned to their families. What about the person who has no family?

Impact of the Pennhurst Litigation

No mentally retarded person who requires a service in our State has been spared. At this time, families who have kept their mentally retarded family member at home are probably the most severely penalized, outside of those residing in our State centers, where services are not comparable or are nonexistant.

Statistically, we serve about 39 percent of our identified need in some way. Our Pennsylvania Governor's office budget projections through 1988 show that we will serve 40 percent of need by that time. We have been pouring millions of dollars into new services for over 10 years. We would need 60 percent more than we currently are spending and can reasonably allocate to fund unmet needs. Community advocates see our ICF/MR Federal funds to State centers as their alternative to State funding constraints. Our State centers care for our most debilitated population. They will require as much, if not more money, for community care. Federal court ordered placements can range from $165 to $225 per diem. I know, because I have been the advocate in situations documented in court record.

Recently, I was involved with a class member in a hearing master procedure that resulted in what is a pleasant placement in a small residential community close to very caring parents who are almost 80 years old. That placement cost $185 a day

and we had to withhold acceptance until that mentally retarded man had a private room which was equivalent in size to what he had at Pennhurst, so he could take his possessions. The semiprivate room would not have cost less. That provider serves 40 people in groups of about 3 or 4 persons. His budget for leased vehicles with maintenance, is about $70,000 annually.

At Pennhurst Center, New Horizons building needed a bus for our 125 severely profoundly retarded residents. No State funding was available, so the staff raised the money over a 2-year period to provide our people with a new vehicle. We have just been told that shopping trips off grounds are cut. We only recently pressured to have $50,000 restored to our budget for fruit juices (they had been giving residents colored sugar water). Ice cream and goodies have been gone for a long time.

I think you will agree that there is discrimination in Pennsylvania between institution and community living arrangements. To eliminate the institution is not the answer to a growing problem. It is a natural setting for a good resource center, an appropriate inpatient and outpatient service for certain kinds of people, and a place where longevity of employment provides experience and knowledge which can be shared. With an open community-institution policy, I am convinced that we could provide far better service to many more people, gain family and community acceptance, and get the best possible return for our financial investment. This ties in with our Pennsylvania League philosophy, "a full range of alternatives with equitable opportunity for all mentally retarded people." Competition for the available dollars (with opportunity for profit) invites investors—not always professionally qualified.

We need medicaid money to assist congregate facilities that serve a severely profoundly multihandicapped mentally retarded population that is socially the least desirable, most fragile, behaviorally difficult, and very costly to support on a scattered basis. In the community, these people will be the first to be rejected when funding cuts must be implemented. This is not a population that we can send home—or should.

Why Institutions for the Mentally Retarded Must Not Be Closed by a National Mandate

Our alternative system to institutionalization is not yet a proven quantity for everyone. We must not destroy any part of a human service system which is the only established public resource available as a backup for the truly needy during this period of intense effort to implement radical change which may or may not benefit the persons who require our support to survive.

Winifred Halderman, chief plaintiff in the Halderman litigation, has said, "I will see my daughter dead first. She will not live in the community." (Pro-Con Public TV, Channel 12, Philadelphia, December 17, 1982. A VCR tape is available.) Caring parents know their family members best.

We parents are accused of being overprotective of our family members. We see this as a desperate attempt to take away family control. Example, just 18 months ago, we tried to have a guardianship law enacted. We were opposed by mental retardation advocates.

Institutions are not all bad and community living arrangements are not all good. Private licensed facilities, referred to as PLF's, are institutional in size. They offer mentally retarded people the most cost effective residential alternative in Pennsylvania. Cost figures show that some PLF's are less than one half the cost of comparable care in a CLA. Private licensed facilities have campus-like settings, on-ground professionalism, closer relationships with their families, and acceptance in their communities. This makes them a proven positive on the side of the congregate way of life. Colleges and universities are institutions. We hear, "But that is different." True, it is, but only because of the commitment to that concept for development and growth in human beings who are capable of learning. Some professionals say we have pushed our mentally retarded people too far.

Pennsylvania can use every available residential alternative. There are priority lists of desperate people and families waiting for services. Why? Because a normalization philosophy currently in vogue here (but already outdated in other States—they are returning to larger facilities) has erroded commitment to a system that should not be eliminated until it can be clearly demonstrated that:

(1) Small is better than large. Conclusive studies do not exist. There are studies by groups funded by advocates for "small" that select their subjects. Growth and development comparisons in the two groups are often based on situations which are not comparable, giving an "apples and oranges" result.

(2) There is an ongoing commitment to the funding of private vendors using tax moneys at per diems which I had quoted earlier in this testimony.

SOME PEOPLE ARE JUST NOT GOING TO BE ASSIMILATED INTO SOCIETY

We have a moral commitment to our handicapped mentally retarded people as fellow human beings, but our society is not always ready to recognize that fact. Legislation will not change that attitude.

WHY OUR PARENTS OPPOSE THE PROPOSED 1983 COMMUNITY LIVING AMENDMENTS

(1) As class members in the Halderman litigation, we have been subjected to orders from three levels of our Federal courts, as well as the ongoing attempts of our own Pennsylvania Office of Mental Retardation to implement a philosophy not mandated by State or Federal statute. The opportunity to be heard by your committee is a rare privilege. If you read the attached exhibits, you will better understand our concerns. There are no rights for parents. Yet, when there are system failures or deficiencies, the parents are called upon to pick up the pieces.

(2) We do not accept the conflict of interest role by advocates who are ultimately the recipients of funding as providers. In mentioned earlier in my testimony that I recently participated in a proposed new mental retardation procedures act for Pennsylvania. Our committee input addressed the issue of "no participation by persons who would benefit from the outcome of a review panel decision." Pennsylvania League supports that concept.

(3) We must question the motivation of advocates for mental retardation services when they are already very much involved in the provision of services dependent on public moneys which are shrinking in our present economy. The Pennsylvania League sees a need for, does support, and would participate in a reevaluation of our public system, but not the precipitous dismantling of the one existing system. We see a need for a fair and adequate study of replacements with a well monitored, extended transition period.

(4) Normalization is a commendable philosophical approach to care, but, "What is normal?" "What does least restrictive mean?" Our study committee spent 2 days trying to agree on a definition. A review of individual State mental retardation statutes definitions shows a wide range of interpretations as to the meaning of "least restrictive."

(5) Pennsylvania League's advocacy experience on behalf of Cresson Center families clearly showed a "no interest" attitude by ARC's in this State in this public service problem until they could not have their community living arrangements.

(6) Operation Real Rights and Pennsylvania ARC do not speak for all parents either here or nationally through NARC. In a conversation with a California ARC board member on June 29, 1983, I learned that they have adopted a resolution in opposition to the 1983 Community Living Draft Proposal. I was advised that the State of Virginia has a similar resolution.

There is an informal national alliance of organizations all similar to Pennsylvania League. We are known as "Informed Parent Network"—you will hear more from us. We want you to know that ARC's and Operation Real Rights do not speak for us.

Thank you for the opportunity to present a consumer perspective on this very controversial issue.

PENNSYLVANIA LEAGUE OF CONCERNED FAMILIES OF RETARDED CITIZENS, INC.

POLLY SPARE, PRESIDENT
P O Box 1133, DOYLESTOWN, PENNSYLVANIA 18901, (215) 348-4059 or (215) 348-4029

February 23, 1983

ANALYSIS AND COMMENT ON
GOVERNOR RICHARD T. THORNBURGH'S
PROPOSED GENERAL FUND BUDGET FOR
DEPARTMENT OF PUBLIC WELFARE
1983-1984

This analysis will be limited to Mental Retardation Service proposals, pages 594-599 and 648-659.

RESIDENTIAL CENTERS (Pages 594-596)

Resident Capacities (Page 594). According to D.P.W. figures, Projected Populations 1983, statewide our census will be reduced by only 27 persons by October, 1983, involving a total "Center" budget reduction of $5,279,000 (page 594). Page 659 shows a "Center" reduction of $5,623,000 for 250 placements. Obviously there is a need for clarification.

Total Projected Expenditures - 11 State Centers (Pages 594-596). Annual costs per client range from $37,123 at Selinsgrove to $67,436 at Woodhaven. The chart below shows a range of annual costs per client and changes in State and Federal funding for four State Centers.

Name of Facility	Annual Cost per Client, 1983-84	Change in State Funds 1981-82 to 1982-83	Change in State Funds 1982-83 to 1983-84	Change in Federal Funds 1981-82 to 1982-83	Change in Federal Funds 1982-83 to 1983-84
Polk	$ 44,685	- 11%	- 6%	+ 57%	- 4%
Embreeville (1)	51,849	+ 3	+ 6	+ 11	- 6
Pennhurst (2)(3)	62,235	- 34	- 15	+ 58	- 4
Woodhaven (4)(5)	67,436	+ 60	+ 6	- 21	- 7

Footnotes:

(1) Embreeville received 13 Cresson residents when that facility closed in December, 1982. The 6% increase from 1982-83 to 1983-84 represents $444,000. At $51,849 per client, over $674,000 would be needed to care for the increased population. At the time of transfer, Embreeville was on a "provisional license" for I.C.F./M.R. due to program and staffing deficiencies.

(2) Recommend review of Pennhurst employee and client payroll printouts. In late 1982, several O.M.R. Harrisburg staff were being charged off in full on Pennhurst's budget. The Special Management Unit (formerly P.I.T.) in 1982-83 accounted for an $8,000,000 cost factor. There were two per diems, $149 per day without P.I.T., $163 per day with P.I.T.

(3) Since 1981-82, Pennhurst has been cut $13,000,000 in State funds.

(4) Woodhaven has had only a +12 person census change since October, 1981.

(5) Woodhaven also receives special services, programs and staff through a multi-million dollar grant to Temple University which is not reflected in these figures. I do not know where it appears in the proposed budget.

QUESTION: Why has D.P.W. chosen to lose $10,000,000 in Federal I.C.F./M.R. funds? This figure is the total of reductions in each of 10 State Centers (one had a slight increase). M.R. Units are not included in this total.

M.R. CATEGORY ANALYSIS (Page 648)

This narrative is the 1983-84 result of years of pursuing the developmental and philosophical approach to provision of programs and services. It in no way resembles any law (M.H.-M.R. Act of 1966) which our Pennsylvania Legislature has enacted. Passage of that legislation did not mandate least restrictive alternative, normalization, C.L.A.'s, I.C.F./M.R.'s. These all came much later. C.L.A.'s were first funded in 1972 (see page 655). These programs were developed through regulations, interpretations, expensive prolonged litigation (the Pennhurst case), etc.

Our present program is very expensive, chaotic, heavily administrative (at the expense of direct care). It offers great business opportunity, a chance for profiteering from our mentally retarded people using public tax dollars. By its own admission, the O.M.R. program is trial and error.

It is frightening to read that D.P.W. considers the closure of Harrisburg M.R. Unit, the C. Howard Marcy Center and Cresson Center an "accomplishment". What this analysis does not go on to tell you is that the Cresson closure was "accomplished" without parental input or consideration after initial promise by O.M.R. in the Fall of 1981 for "Better than what you have now". There were no programs developed in the receiving facilities prior to transfer in most cases. Neither families nor clients were granted any rights. O.M.R. regulations (December, 1981 re: transfers) were not observed.

Cresson will be used for a jail. The criminals who will occupy it have all the rights.

We feel that small I.C.F./M.R.'s will become very expensive mini-institutions for very involved clients. New York State tried it. In late 1980 they published a report documenting reasons for looking to the "larger" facility (more than three beds) and called for immediate closure of the smaller units.

MENTAL RETARDATION SYSTEMS SUPPORT (Pages 649-650)

Program Measures. The 106,740 persons identified on line 2 as eligible for M.R. Services represent about 50% less than D.P.W. figures used in the final report of the Senate Investigative Task Force and the Proposed 1982-83 Budget, page 659. The use of Chase Econometrics is a very recent change.

Since 1967, all Pennsylvania counties have prepared, annually, detailed individual county plans developed according to O.M.R. guidelines with information including projections of need for various services mandated by the M.H.-M.R. Act of 1966. These plans take months to prepare and must be publically reviewed and approved by the county M.H.-M.R. Advisory Boards and County Commissioners. Are they all inaccurate? Useless?

Sixteen years of a mandate ("66" Act) has, according to line 4, page 649, developed services for 39% of identified need. By 1987-88 we'll provide 40% of need. What about the other 60%? Is there any plan to serve these people? The cost of serving 100% of need at this current rate would be staggering.

COMMUNITY BASED SERVICES (Pages 651-653)

Persons on Waiting List to Receive Adult Day Services (Page 651, line 8). These figures show a gradual increase from 2,160 persons in 1982-83 to 3,175 by 1987-88 (47%). Line 9 increases by 3% between 1982-83 and 1983-84 and then remains unchanged through 1988. Are there to be no more adult needs?

As an advocate for community families in my small county, I would estimate that we could easily use 50% of the available 250 placements planned for 1983-84.

Family Resource Services (Page 652). This is a vital support for families who have retarded members in their homes and no alternatives. The last paragraph says that 11,504 persons were provided one or more services in 1981-82. (That could be a two hour baby sitting service or a week at camp.) According to line 7, page 651, under Program Measures, only 11,504 persons will be provided one or more services through 1988. Not much progress!

COMMUNITY RESIDENTIAL SERVICES (Pages 654-656)

The emphasis is preparation of persons who cannot live at home to become prepared for economic self-sufficiency and independence. There is a D.P.W. admission that fewer persons will achieve the goal of "independence" due to increasing numbers of severely profoundly retarded persons who will be entering C.L.A.'s. What C.L.A.'s?

According to Program Measures, page 654, lines 3 to 5, from 1983-84 to 1987-88 only 4,440 people will live in C.L.A.'s and the numbers of persons provided C.L.A. services after 1983 will be decreasing. Between 1982-83 and 1987-88 the number of C.L.A. residents transferred to independent living or returning to families gradually reduces by 83% from the 1982 level.

Recommended Program Costs (Page 654). Costs will increase by 20% from 1983-84 to 1987-88, but plans for C.L.A. placements directly from the community (see line 1, Program Measures) and from the institutions (line 2, Program Measures) are each decreasing 53% by 1987-88.

The last paragraph under C.L.A., page 655, proposes $4,223,000 in total funds for 250 placements, or $46 per day, $16,892 per year. Impossible!

QUESTIONS:

1. Why are expenditures increasing when C.L.A. placements are planned to be reduced?
2. Where do we find any provider who will take severely profoundly retarded persons for $16,892 per year? Judge Raymond Broderick recently ordered over $175 per day ($64,000 per year) for each of two former Pennhurst clients in Montgomery County. $46 per day is irrational and unavailable.
3. What about existing and future court orders?
4. Is there any contingency plan?

Private Licensed Facilities (P.L.F.'s) (Page 656). In our 1982-83 budget analysis we supported the need to retain this most valuable Pennsylvania resource which is being constrained by regulation. It is, we repeat, far more cost effective, more easily cost controllable and more manageable than small scatterred facilities.

Wisely, in 1982-83 our Pennsylvania Legislature "line-itemed" P.L.F.'s, separating and assuring their funding. We recommend continuation of that approach. State dollars would be wisely invested in P.L.F. quality programs.

CONCLUSION

Pennsylvania League questions some of the language of this budget. We find it lacking in reality. Some statistics are very questionable. It is difficult to accept D.P.W.'s least restrictive emphasis when this alternative is not really adequately available or planned to be through 1988.

The Commonwealth as a Petitioner in the U.S. Supreme Court on Writ of Certiorari from the U.S. Third Circuit Court of Appeals has just submitted a Reply Brief for Petitioners that references on page iii under Other Materials (Table of Authorities) studies which question the utilization of "least restrictive alternative". If "least restrictive" is our Pennsylvania position (which the budget seems to indicate), why did we take this Pennhurst case back to the U.S. Supreme Court for a second time on February 22, 1983?

My card is attached. I am available to answer questions.

Sincerely,

Polly Spare,
President

ITEM 2. STATEMENT OF THE PENNSYLVANIA ASSOCIATION OF RESIDENCES FOR THE RETARDED

The Pennsylvania Association of Residences for the Retarded is a nonprofit association representing private providers of residential services for the mentally retarded throughout Pennsylvania. Since its inception in the late 1960's, PARR membership had reflected a full array of residential programs, consisting of private licensed facilities (PLF's), intermediate care facilities for the mentally retarded (ICF's/MR), and community living arrangements (CLA's). Currently, PARR represents one-third of all private residential beds in the Commonwealth; furthermore, more than one-half of the State's total ICF/MR beds are reflected in association membership.

Since the recognition of private residential alternatives in the early 1970's, association policy has stressed a continuum of services as the framework for the State's mental retardation delivery system. In attaining what many refer to as "deinstitutionalization," PARR firmly believes that only a broad spectrum of services in the community can fulfill the needs of the mentally retarded in settings most appropriate to his/her individual needs. This commitment to a continuum of services bears even greater relevance to today's movement of the more severely retarded and multiply handicapped into the community. To match the special needs of this increasingly diverse population, we must maintain a variety of specialized services. Ultimately our mental retardation delivery system must offer quality service, quality management, and the freedom to choose a program in long-term care.

As reflected in PARR's own membership profile, Pennsylvania presently operates a variety of residential programs. The categorically-funded CLA's, PLF's, and ICF's/MR differ substantially in size, location, and program philosophy. They include apartments, small and large group homes, special villages, campuses, and hospital-like homes in settings that are urban, suburban, and rural. Despite this strong start in program diversity, Pennsylvania can still only boast of a partial continuum of services. Although many quality residential services exist, there lacks sufficient funds, sufficient support services, and adequate direction for the State to guarantee a reliable and complete spectrum of services.

What's missing is a clear, consistent, and comprehensive State policy for the placement and care of the mentally retarded. And since Federal initiatives often precede State actions, Federal policy also deserves clearer definition. Currently, the mental retardation delivery system operates under changing philosophies, uncertain funding patterns, and a myriad of regulations, all of which, if not coordinated, can serve to undermine a true continuum of services.

Philosophically speaking, we are once again at a crossroad. Just as the 1960's and 1970's carried the furor of the deinstitutionalization, the 1980's are carrying tones of "cost containment" and "limited" role of institutions. Policymakers, providers, and parents are questioning the effectiveness of the community residence movement and the once zealous rush for total desinstitutionalization.

In addressing the ideological climate of the 1980's, PARR maintains that a wide range of service options makes sound, common sense, both from a functional and fiscal standpoint. Given the programmatic realities of providing residential services for severely retarded, medically complex clients, coupled with the economic hardships of today, it is unwise to endorse one end of the service spectrum as the best type of service. Policymakers must exercise caution when hearing isolated incidences of institutional abuse and community MR "street people," sensationalized cases that only breed misconceptions about types of programs. In fact, "warehousing" has been called a "thing of the past" due to the ICF/MR program and court actions that have accelerated improvements in institutional settings. Likewise, in contrast to the deinstitutionalization of the mentally ill, "dumping" of the mentally retarded is not considered a problem.

Therefore, PARR does not support any policy or legislation that would dismantle existing, quality services for the promotion of a selected type and size of program. Under current debate is the proposed "Community Living Amendments of 1983" which would redirect the flow of medicaid dollars to small, community-based ICF's/MR. This shift of funds would exclude many of the existing larger ICF's/MR that have proven to be quality, cost-efficient programs. The proposal's assumption that only small residences can provide the most appropriate homes is unfounded by empirically conclusive research. Federal enactment of this legislation would ignore a host of other elements that also contribute to the quality of care.

Although PARR does not support the emphasis placed on size in the draft act, "Community Living Amendments of 1981," the association does agree with the intent to transfer funds out of expensive, State-operated institutions. Funding, both on the State and Federal levels, should follow those quality programs that operate

at reasonable costs. But, according to data from Pennsylvania's Department of Public Welfare, dollars are not flowing along this logical route. Figures for fiscal year 1981-82 show that the average per diem for State MR centers was $143.45, while private ICF's/MR operated at an average per diem of $87.41. At $56 more per day per person, the publicly-operated institutions are unquestionably less cost-efficient. An unpublished report in 1981 by the U.S. Department of Health and Human Services supports this conclusion—in their assessment, the per diem in institutional ICF's/MR averaged $80, while the community ICF/MR averaged $65 (the study also found per diem rates for institutions in the northeast to be 20 percent higher than in the rest of the country).

The same study points out that non-ICF/MR settings averaged even less per diem rates, averaging only $50 a day, including support services. Despite the cost-efficiency of these private facilities, the bulk of State funds continues to support State institutions. During fiscal year 1981-82, Pennsylvania allocated 46 percent of the total MR appropriations to State centers for the mentally retarded, which at that time served only 17 percent of the entire MR population. As the State centers' populations decline while their per diems rise, it becomes increasingly irresponsible not to redefine the role of State institutions. The centers need not be closed down, for they could serve as useful resources for diagnosis, specialized treatment, research, respite, training, and day programs.

In light of these facts, PARR encourages Federal and State efforts to shift funding from publicly-operated, high cost large institutions to privately-operated residential programs. Many of our State's private residential services have been responsive to needs, innovative, effective and cost efficient. Moreover, the private sector is free of the conflict of interest that inevitably plagues the public sector in its role as program monitor and service provider. If Pennsylvania truly wishes to contain costs in the delivery of human services, then State officials should be eager to implement policies encouraging the operation of cost efficient programs in the private sector, restricting their own responsibilities to funding, regulating, and monitoring.

In summary, the Pennsylvania Association of Residences for the Retarded supports a continuum of residential services, one which offers choice in the selection of long-term care. Pennsylvania should strengthen the existing network of fine, private residential facilities that have made deinstitutionalization effective and cost-efficient throughout the Commonwealth. We should not abandon existing, quality CLA's, PLF's, or ICF's/MR in favor of a particular service mode especially under current fiscal limitations, and in light of the fact that no one type of service has been universally accepted as the most appropriate.

To fill in the gaps along the present service continuum, there must be greater clarification and consistency in State and Federal policies with regard to the care and placement of the mentally retarded. New policy should shift funds out of expensive, public institutions to residential programs in the community, and in so doing, redefine the appropriate role of State MR centers. Finally, the role of government must be reexamined. Pennsylvania's Department of Public Welfare should restrict its responsibilities to matters concerning funding, regulations, and monitoring mechanisms.

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